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ABSTRACT

Designed for vocational rehabilitation counselors, this book provides information about diabetes and treating diabetes. Much of the material previously appeared as articles in "Voice of the Diabetic" and is written not just by doctors and diabetes professionals, but also by members of the National Federation of the Blind (NFB) Diabetes Action Network, and people with personal experiences, encouragement, and insights to share. Part 1 provides an introduction to diabetes and includes: "Myths about Diabetes: What You Tell Your Clients" (NFB Diabetes Action Network); "What Is Diabetes Mellitus?" (Arturo Rolla); "Diabetic Dye Disease" (Prema Abraham); and "A Note on 'Brittle' Diabetes" (NFB Diabetes Action Network). Part 2 addresses self-management and includes: "New Dietary Guidelines for Diabetes Management" (Mimi Moore); "Review of Oral Diabetes Medications" (Peter J. Nebergall); "Diabetes and Exercise" (NFB Diabetes Action Network); "About Insulin" (NFB Diabetes Action Network); "Insulin Measurement Devices" (NFB Diabetes Action Network); "Blind Diabetics Can Draw Insulin without Difficulty" (Ed Bryant); "I've Gotten Attached to My Insulin Pump" (Veronica Elsea); "New Insulin" (NFB Diabetes Action Network); "Talking Blood Glucose Monitoring Systems" (Ed Bryant); "Non-Invasive Glucose Monitors" (NFB Diabetes Action Network); "Diabetes and the Feet" (NFB Diabetes Action Network); and "Medicare Pays for Diabetic Footwear" (NFB Diabetes Action Network). Part 3 discusses current medical issues and includes: "Kidney Failure, Dialysis, and Transplantation" (Ed Bryant); "Pancreas Transplantation: Should Blind Diabetics Be Excluded?" (Francisco S. Escobar); "Arthritis and Diabetes: A Common Association" (Thomas Pressly); "Diabetes and Yeast Infections" (Diana W. Guthrie); "Hypoglycemia and How to Deal with It" (Ed Bryant); "Diabetic Peripheral Neuropathy" (NFB Diabetes Action Network); "Diabetes and Men's Sexual Health" (Ed Bryant); "Diabetic Ketoacidosis" (NFB Diabetes Action Network); and "Necrobiosis Lipoidica Diabeticorum" (NFB Diabetes Action Network). Part 4 focuses on employment issues and includes a series of articles by the NFB Diabetes Action Network, including: "Diabetes and the IWRP"; "Blind Diabetics at Work"; "The Use of Braille by Blind Diabetics"; "Health Insurance"; and "Scleral Shells." Part 5 addresses emotional aspects of diabetes and includes: "The Emotional Side" (NFB Diabetes Action Network); "How I Went Blind...and Then What" (Ed Bryant); and "My Transformation" (Betty Walker). An appended list relates informational resources and product resources. (CR)

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Serving Individuals with Diabetes who are Blind or Visually Impaired:

A Resource Guide for Vocational Rehabilitation Counselors

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SERVING INDIVIDUALS WITH DIABETES WHO ARE BLIND OR VISUALLY IMPAIRED:
A Resource Guide for Vocational Rehabilitation Counselors

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SERVING INDIVIDUALS WITH DIABETES WHO ARE BLIND OR VISUALLY IMPAIRED:
A Resource Guide for Vocational Rehabilitation Counselors

INTRODUCTION

In a publication like this, both economy and precision are essential, particularly as persons from outside specialized disciplines encounter "terms of art" within those fields. The editors of this monograph have therefore attempted to use terminology which bears some explanation at the outset to avoid confusing or misleading the reader.

Without categorically adopting Humpty-Dumpty's approach that a word means what we say it means, we have attempted to use a few terms in a specific way for this publication:

Blind is used here to cover a wide range of visual impairments that necessitate use of alternative techniques to the usual visual ones for vocational and daily living activities. For our purpose, it includes those who are (a) legally blind according to the Social Security Administration's definition (central visual acuity in the better eye with best correction of 20/200 or less or a limitation in the visual field which subtends an angle of 20 degrees or less [tunnel vision]); (b) visually impaired (commonly describing, for example, a central acuity ranging from 20/70 to 20/200); and (c) those whose visual limitation necessitates use of some combination of the alternative techniques of blindness and sighted techniques in order to function efficiently, regardless of tested visual acuity or field.

The rationale for extending the term to cover all of these groups is the need to address the mix of clients which the readers of this publication may find themselves serving since state agencies and even separate agencies for the blind may, under their respective state enabling statutes, find themselves serving persons from any of these groups.

Secondly, in the interest of economy, we have chosen to use references to "clients," "individuals," "persons," or "people" to refer in this specialized context to clients of state rehabilitation agencies who are blind (as defined above) and who have a form of diabetes. Such references will be clear from the context or else clarified in the text. This limited usage seems reasonable given the intended audience, and it will certainly preserve the patience of those readers with limited time for reading.

One more caveat is in order. *The information and advice contained in this publication is intended to serve educational purposes and is not intended to take the place of personal instruction provided by a person's doctor or health care team. Clients should discuss any changes in treatment with appropriate health care professionals.* With this fact in mind, the editors and contributors hope the material will shed light on a number of issues surrounding diabetes, dispel some of the mythology and misinformation about the condition, and serve as a stimulus to further research.

Finally, where reviewers wished to make observations about articles written by others, they appear as footnotes at the end of each article. This seemed the fairest method of sharing those comments without violating the integrity of authors' contributions.

The National Federation of the Blind (NFB) is pleased to produce this monograph in partnership with the Rehabilitation Research and Training Center (RRTC) on Blindness and Low Vision at Mississippi State University. A central part of the mission of both organizations is to serve people who are blind by providing sound and helpful information on all aspects of blindness and services to blind persons. This project is an outgrowth of our commitment to do so. Final editing was done by RRTC staff in conjunction with NFB staff.

This work grew out of a realization that, although there are many specialized texts of high quality available to the diabetes professional, there has long been need for reference material on "the diabetes experience," written to reflect the accomplishments of diabetics. With the increasing complexity of health care comes a strong temptation to specialize and compartmentalize--and consequently to dismiss as "unscientific"--the patient's personal experience with the condition. "Us and them" thinking is usually counterproductive, but much more so when the clients's compliance with best medical knowledge is critical to the preservation of health. Passage of the Americans with Disabilities Act in 1990, which defined both blindness and diabetes as "disabilities," has only heightened the need for understanding of both in the population at large.

Recognizing that learning about the condition is the key to successful self-management, many diabetics study extensively, becoming well-versed in the specifics of the condition. However, many rehabilitation professionals (both counselors and teachers) lack personal connection to the condition, and to them and their clients our book is addressed.

Diabetes carries its own special baggage, and more so when coupled with vision loss. Diabetic retinopathy runs the gamut from almost undetectable "background" retinopathy, through "fluctuating vision" (a condition in which sight may change from functional to non-functional, and perhaps back again, within a few hours), to permanent and total loss of sight. Through all of this the daily tasks of self-management (which many carried out for years before losing their sight) must go on.

And they do go on, as the following articles detail. Thanks to some fine pieces of adaptive equipment and their own (too often underestimated) abilities, your diabetic clients are fully capable of independently self-managing their condition. Having cleared that hurdle, they are productive members of society, fully capable of participation in the mainstream. The old ideas that self-management was a straightforward mathematical equation and that diabetes complications were proof of personal failure are being discarded in the face of the truth.

What is needed to advance this new and positive approach is a two-pronged attack: Mastery of the equipment and techniques that enable diabetics to manage their condition safely and efficiently and fostering of a positive attitude towards their abilities and capabilities. For if members of a particular group are taught to believe they can't do very much, how many individual members will defy their lessons? The instructor who communicates a positive attitude inspires clients to incorporate the same into their vocational and life-planning goals, and to achieve to their true capacities. The old stereotypes are wrong (they were wrong when they first appeared back in the Middle Ages!).

Much of the material included in this book previously appeared as articles in *Voice of the Diabetic*, the free quarterly newsmagazine published by the Diabetes Action Network of the NFB. All were prepared by or for the Network. In 1985, moved by the facts that diabetes is the leading cause of new blindness in the U.S. and all diabetics are at risk of ramifications, members of the NFB founded the Diabetes Action Network. Furthering its goal of providing mutual support and information for individuals with diabetes, the Network began publication of the *Voice* in 1986.

Voice articles are written not just by doctors and diabetes professionals, but also by Network members, people with personal experience, encouragement, and insight to share. Unlike the doomsayers who occasionally have dominated the field, the *Voice* is always upbeat and positive, helping to show persons with diabetes who are blind, those losing vision, and those facing ramifications that they are not alone and regardless of complications, they do have options.

The *Voice* is the largest publication in the blindness and diabetes field, and the largest diabetes publication offered in accessible format

(15/16 i.p.s. audiocassette). It is offered free on request. For more information, readers are invited to contact the National Federation of the Blind, 1800 Johnson Street, Baltimore, MD 21230; telephone (410) 659-9314; Fax (410) 685-5653.

PART ONE: INTRODUCTION TO DIABETES

Myths About Diabetes: What You Tell Your Clients

NFB Diabetes Action Network

It is human nature to fear the unknown. Tribesmen told stories of trolls and demons; early sailors kept watch for sea monsters. We're still afraid of not knowing--and we tell a lot of tall tales about diabetes! Scary stories fill a void when we don't know the truth, and they disappear when the truth is known. Here are a few myths about diabetes and how you might approach clients with the facts which dispel them.

"*I got it from eating sugar.*" Overindulging in sugar isn't good for anyone. Usually the preceding statement means sweets, which also have LOTS OF FAT, so the end result can be a serious weight problem, not to mention extra trips to the dentist. People who eat quantities of cakes and ice cream often miss essential nutrients found in other foods...but their bad eating habits do not cause diabetes. In fact, doctors and researchers are still unsure what causes diabetes. There appear to be a number of factors, some of them genetic. Once diabetes appears, gorging on sugar is a bad idea--but it DOESN'T cause diabetes.

"*I'm gonna' go blind.*" Although it is true that all diabetics are at risk for ramifications of diabetes, such as blindness, heart problems, and renal disease, it is equally true that only a small percentage actually experience the full force of such complications. The Diabetes Control and Complications Trial proved that the better the blood sugar control, the less the likelihood of ramifications. Anyone already experiencing ramifications of diabetes needs to achieve and maintain the tightest possible control to minimize their further progression.

"*My child will be diabetic too.*" Children and close relatives of diabetics are considered at increased risk to develop the disease. Children, brothers and sisters, and cousins of persons diagnosed with diabetes should all be periodically checked. Current statistics suggest that the child of a parent with diabetes may have, at worst, a 1 in 4 chance of developing it. It is important to remember that diabetes sometimes skips a generation or two, so having a grandparent with diabetes may be significant.

"*Since I don't have to inject, it isn't serious.*" A surprising number of people still believe this myth. Non Insulin-Dependent Diabetes Mellitus (type II diabetes) can produce destructively high blood glucose levels if it is not kept under control. Type II diabetes often grows more severe with time, so a person who starts with "a touch of sugar" will probably need to progress to diet- and exercise-based blood sugar control, then to oral diabetes medications. Many veteran type II diabetics find their "oral meds" have become ineffective with time, and they need to switch to insulin injections to maintain effective diabetes control. Type II is serious, and if one's numbers "aren't that bad," they may merely indicate the early stages of the disease.

"*I'm losing my sight; my kidneys are going; its all over for me!*" The best answer for this antiquated myth is to look at the evidence. Having diabetes is not pleasant, but its ramifications do not present a bar to continued participation in the mainstream of life. With mastery of the proper skills and possession of the proper adaptive equipment, individuals with diabetes can continue to live full lives, even with severe ramifications. Many members of the Diabetes Action Network of the NFB are living examples of just how much is possible once one rejects the idea that blindness, kidney failure, or neuropathy means inability.

Diabetes doesn't mean a quick death either. Many diabetics, even insulin-dependent, live well into old age. With recent improvements in diabetes care, younger individuals with diabetes should do even better.

"*I've gotta' eat that horrible diabetic diet!*" Far from horrible, unless a person is a confirmed junk-food addict, today's diabetic meal plan is a well-balanced, sensible presentation that would be healthful for anyone to adopt, with or without diabetes. And gone are the days when anything with sugar was "off limits." Under today's system, all carbohydrates are counted equally. If those with diabetes want to eat things rich in carbohydrates, they "pay for it" by cutting an equivalent amount of carbohydrates from somewhere else in their diets. There is a lot of flexibility, and the rest is just a matter of care and moderation.

"*I don't need that meter; I can tell if I'm too high or too low.*" This myth is dangerous because it's sometimes true. Sometimes people can sense a "low" without a meter and take appropriate action. Sometimes they can't, and they wind up in the ambulance. Hyperglycemia is harder to detect by "feel," and either way, making do without regular blood glucose tests is like flying without a parachute: it is a gamble. Diabetics are wise to learn their bodies' signals that they are approaching trouble, but it is best to use the glucose monitor to be sure.

"I can't exercise; the stress would make things worse." Physical exercise burns blood glucose, pulling one's numbers down, and decreasing the need for insulin or oral medications. Care is required to make sure one does not drop dangerously low or incur other complications like foot irritations (especially if there is decreased sensation in the feet), but such care is just an expansion of what one should be doing already. The benefits of a carefully planned and faithfully followed exercise program far outweigh the perils. Your client should discuss exercise plans and any adjustment in medications with a doctor first. One might consult with an exercise physiologist as well who has experience in the diabetes field.

The above comprise just a sample of the myths of diabetes. There are hundreds--some scary, some dangerously rose-colored. There is no substitute for knowing the truth. Blind diabetics should pay attention to their bodies and keep ahead of what their diabetes is doing--there is no room for surprises. Consulting with a doctor or diabetes educator is a good way to check.

What is Diabetes Mellitus?--Arturo Rolla, M.D. and Joan Stout

Note: Arturo Rolla, M.D., is an endocrinologist at New England Deaconess Hospital and an associate clinical professor of medicine at

Harvard Medical School. Joan Stout is a professional writer and editor.

Diabetes is a metabolic disorder that occurs when the body cannot properly use glucose (a form of sugar), the body's main source of fuel. During digestion, most of the carbohydrates we eat are converted to glucose, which passes into the bloodstream where it is available to the cells for use as energy. Eighty percent of the glucose in the blood goes to the muscles. But in order for glucose to enter the cells and be used as energy, *insulin*, a hormone secreted in the islets of the pancreas, must be present. Without insulin, the body cannot convert food into energy.

The cells that produce insulin are called beta cells. They are normally stimulated to produce insulin by the rising level of blood glucose. In that way, the body has a system by which the right amount of insulin is secreted for the right amount of glucose present. Once the glucose has entered the cells, the blood glucose level decreases, and the beta cells stop secreting insulin.

Q: What are the different types of diabetes?

A: There are basically two types of diabetes. In one type, the beta cells are destroyed by the immune system and no longer secrete insulin. This is called *type I diabetes* and is characterized by an absolute deficit of insulin. The other type, called *type II diabetes*, is due to "insulin resistance," an initial resistance of the body's cells to obey the orders of insulin. To overcome this resistance, the beta cells secrete more insulin, and glucose is eventually forced into the cells. Glucose is maintained within normal limits, but at the expense of increased insulin secretion by the beta cells. After many years of such increased secretion, the beta cells become "tired" from working overtime, and the fatigue process begins. This fatigue tends to be progressive and over time the compensation of insulin resistance disappears. At that point, blood glucose levels start going up.

Type I diabetes is also called *insulin-dependent diabetes* (IDDM) and was previously known as *juvenile diabetes*. We now recognize that type I can appear at any age, even though it is most often diagnosed before the age of 40. Type I is an autoimmune disease, which means that the body's defense against infection, the immune system, attacks part of the body. In type I, the immune system attacks the beta cells in the islets of the pancreas and destroys them. The pancreas then produces very little or no insulin, and the patient needs daily insulin injections to live. Symptoms typically appear over a brief period of time, although the destruction of the beta cells may occur over a period of months or years. These symptoms include: Increased thirst and urination, weight loss despite increased hunger and food intake, blurred vision, extreme tiredness, and itching. Coma and death can follow if diabetes is not diagnosed and treated.

Type II diabetes is also called *noninsulin-dependent diabetes* (NIDDM) and was previously known as *adult-onset diabetes*. Type II usually occurs in adults over 40, but it can appear at a much earlier age, including early adolescence (*maturity-onset diabetes of the young*, MODY). About 80% of people diagnosed with type II diabetes are overweight. In type II, the pancreas produces insulin, but the body is unable to effectively use it. Insulin resistance is common, and the patient may have large amounts of insulin present in the bloodstream. Symptoms of type II typically develop gradually, over a period of months or years. Symptoms include: Increased thirst, increased urination (especially at night), fatigue, weight loss, blurred vision, frequent infections, and slow healing of sores. Because type II can be present for many years before diagnosis, symptoms may include complications of diabetes, such as heart disease, kidney disease, nerve problems, or vision problems.

Q: What causes type I diabetes?

A: At this point, we do not know why the body's immune system attacks the beta cells and destroys them. The cause may be a virus, an exposure to cow's milk at an early age, genetics, or more likely a combination of factors. Doctors can determine who is at a high risk of developing type I by testing their blood for antibodies against the islets in the pancreas and by testing their capacity to secrete insulin. The hope is to prevent further beta cell destruction.

Q: What causes type II diabetes?

A: Most people who develop type II diabetes are overweight. Overweight people have excess adipose tissue in the body, and the extra fat increases their resistance to insulin, not only in the fat tissues but also in all the other cells. Diabetes is not caused by eating too much sugar, but being overweight increases the chances of developing type II diabetes.

Q: Who gets diabetes?

A: The following people have an increased risk for developing diabetes:

- people with family members who have diabetes,
- people who are overweight,
- African Americans,
- Native Americans, and
- Hispanics.

These risk factors are much higher for type II than for type I, although a genetic component is present for both types. For type II diabetes, risk factors include older age, increased weight, decreased level of physical activity, overfeeding or too rich diet, and family history of diabetes. Adults are much more likely to get type II diabetes than are children, whereas type I tends to appear more frequently in children.

Q: How many people have diabetes?

A: In 1995, the estimated prevalence of diabetes in the United States was 16 million people, about half of them not yet diagnosed. For type I diabetes, the estimate of diagnosed cases ranges up to 800,000. About 30,000 new cases of type I are diagnosed each year. For type II diabetes, the 1993 estimate was 7 million to 7.5 million diagnosed cases. About 595,000 new cases of type II are diagnosed each year. Approximately 4.2 million women and 3.6 million men have been diagnosed with diabetes. For children age 19 years or younger, the estimate is 100,000 cases. For adults age 65 years or older, the estimate is 3.2 million cases.

Q: How is diabetes treated?

A: Daily insulin injections are required to treat type I diabetes. Many people with type I take multiple injections daily. A regimen of three or more injections per day is called "tight control" or "intensive management." The insulin must be balanced properly with food intake and exercise (including regular daily activities). Frequent blood testing is performed by the patient to monitor blood sugar levels. This involves pricking a finger for a drop of blood, applying the blood to a test strip, and inserting the strip into a small machine that reads the strip and displays the approximate level of blood sugar. Type II is sometimes treated with diet and exercise only. Oral diabetes medications, which are not insulin, are also used. If these methods do not work, type II is treated with insulin. People with type II must also balance their exercise and food intake with their medication (whether oral medication or insulin). A weight loss diet is frequently a part of treatment with type II. Blood glucose testing by the patient is also an important part of treatment.

Both type I and type II diabetes are best treated with a team approach, with the patient being the most important part of the team. The goal of treatment is to keep blood sugar levels as close to normal as possible to prevent long-term complications. Since most of the daily care is the responsibility of the person who has diabetes, patient education is imperative. Other team members should include a diabetes doctor (endocrinologist or diabetologist); specialists as necessary (ophthalmologist, podiatrist, etc.); a dietitian; and a diabetes educator.

A 10-year study called the Diabetes Control and Complications Trial (DCCT) was completed in 1993. The study included over 1,400 people with type I diabetes and compared the results of intensive management with "standard" management. The participants who followed intensive management, keeping their blood sugar at lower levels, had significantly lower rates of eye, kidney, and nerve diseases than did the "standard management" group. Although the study focused only on type I diabetes, most doctors believe that people with type II will also benefit from keeping their blood sugar as close to normal as possible.

Q: What are the complications of diabetes?

A: Complications of both type I and type II include eye disease and blindness, heart disease, strokes, kidney disease and kidney failure, amputations, nerve damage, skin infections, and gum disease. Diabetes can also cause complications of pregnancy and congenital malformations. In 1992, diabetes contributed to at least 169,000 deaths. In 1993, diabetes was the seventh leading cause of death listed on death certificates in the United States.

Q: How much does diabetes cost?

A: In 1992, the total cost of diabetes in the United States was estimated at $92 billion. This includes $45 billion for direct medical costs (only those costs directly attributable to diabetes) and $47 billion for indirect costs such as disability, work loss, and premature deaths.

Diabetic Eye Disease

Prema Abraham, M.D.

Dr. Abraham is director of vitreoretinal and retinovascular services at Black Hills Regional Eye Institute in Rapid City, South Dakota.

Introduction

Diabetes is a common medical problem which affects the body's ability to regulate blood sugar levels. Over a period of years, high blood sugar will damage small blood vessels in the body and often cause problems such as kidney failure, sensory abnormalities in the hands and feet, and eye problems. The focus of this section is to describe how diabetes affects vision, what specific factors contribute to visual loss, and the technological advances that are available today to evaluate and manage diabetic eye disease. Although in the worst cases, an individual may suffer permanent loss of vision in one or both eyes, it is important to remember that most people who carefully control their diabetes and get good eye care can prevent many of the visual complications of the disease.

Diabetes is present in approximately 3% of Americans; however, individuals in special populations such as Native Americans and the elderly are much more likely to suffer from the disease. For example, nearly 50% of some Native American groups are affected, and among the nation's elderly, about 15% are affected. Because one form of diabetes (i.e., adult-onset or type II diabetes) may be present in a person for several years before the diagnosis is established, some of the preventable complications may already be in the early or moderate stages when the diagnosis is finally made and treatment initiated.

What is Diabetes?

Diabetes is much more than having an elevated blood sugar level. It is a complex endocrine disorder which can affect many aspects of the body's metabolism, changes in which can have detrimental effects on a variety of vital organs. Left unchecked, diabetes may result in complete kidney failure and require the use of hemodialysis. The disease also causes heart disease and is a potent risk factor for heart attacks. Nerve endings can also be severely damaged, leaving the patient with a painful burning sensation in the hands and feet or causing numbness in the same areas. This loss of sensation places the diabetic at increased risk of injury without being aware of the damage. The numbness, along with the detrimental effects that diabetes may have on the immune system, increase the risk of serious infection. Eye damage from diabetes may include any one or a combination of problems such as cataracts, glaucoma, loss of night vision, double vision, eye infections, fluctuating vision, and retinopathy--a broad category of problems affecting the retina.

There are two categories of diabetes, one which often affects individuals at a younger age (type I) and the other which affects middle-aged and elderly adults (type II). Both types are associated with elevated blood sugars, but the complications of the disease may vary in severity and rate of onset and progression depending on the type.

How Does the Eye Work?

To understand how diabetes affects the eye, it is important to know how the normal eye functions. The eye works very much like a camera, with a focusing lens in the front and the film in the back. The retina plays the role of a camera's film, receiving the image of the object at which the camera is focused. The retina, which is actually a direct extension of brain tissue, transmits the visual information through the optic nerve to areas of the brain which process it into vision. In a camera, no matter how clear or strong the lens and how perfectly focused the image may be, if the film is not working well the camera will not take good pictures. Similarly, if the retina is diseased, vision will be impaired no matter how clear and strong the lens may be. Furthermore, if the space between the lens and the retina is obscured with blood or other material, vision will be impaired.

When a diabetic goes to the ophthalmologist, the doctor looks carefully at the retina. With special instruments, the blood vessels which normally travel through the optic nerve can be viewed as they branch out and nourish the retina. One small but particularly important area of the retina called the *macula,* is sometimes referred to as the "sweet spot" of the retina. This "sweet spot" is the area responsible for detailed vision required for reading, driving, needle-threading, and other similarly detailed visual functions. The remainder of the retina is for side or *peripheral* vision and not useful for fine vision. In order to maintain meaningful vision for activities such as reading, it is essential that the macula remain healthy and unobstructed. If the macula does become damaged or covered with blood, the eye does not necessarily become blind. It is possible that the side vision will remain fully functional but reading and identification of faces will be extremely difficult or impossible. For example, it may be possible to perceive that someone is approaching, but without the "sweet spot", it will be impossible to identify that person visually.

What is Retinopathy?

Retinopathy is the general name given to diseases of the retina. In persons who have diabetes, it can take a variety of forms and may affect those with either type I or type II diabetes. Those with type I are usually free of retinopathy for the first 5 years after diagnosis because there is rarely much time between disease onset and diagnosis. On the other hand, because they may have had the disease for several years prior to diagnosis, those with type II may already have diabetic eye problems at the time of diagnosis or shortly thereafter.

The principal problem of the retina caused by diabetes involves the very fine blood vessels which nourish the nerve tissue. High blood sugar causes these vessels to become damaged and then leak fluid and fatty material into the nerve tissue of the retina. The retina becomes swollen and does not function normally. This form of retinopathy is called *background* or *non-proliferative retinopathy*. The medical term for swelling is *edema*; when this process involves the "sweet spot" of the retina, it is called *macular edema*.

Another more serious form of diabetic retinopathy is called *proliferative retinopathy*. Like the non-proliferative form, this form is initiated by high blood sugars over a period of years. However, in the proliferative form, the damage inflicted on the small retinal blood vessels results in impaired blood flow to the retinal tissue. Some vessels actually close off completely and deprive an area of the retina of much needed oxygen and other blood-borne nutrients. Consequently, the oxygen-deprived tissue sends out a signal which stimulates the growth of new blood vessels. Unfortunately, the new vessels are distinctly abnormal and are the source of many serious diabetic eye complications.

How is Retinopathy Treated?

As with many chronic conditions, the best management strategy is based on prevention. With diabetes this means careful and consistent blood sugar control. Equally important are frequent eye evaluations which may permit early detection and treatment of retinopathy. When the eye doctor examines the retina of a patient with diabetes and discovers evidence of retinopathy, the next step usually involves obtaining special photographs of the retinal blood vessels. This process, called *fluorescein angiography*, utilizes a fluorescent dye injected into an arm or hand vein which then circulates throughout the body. When this dye flows through the retinal blood vessels, a series of photographs can be taken with specialized camera equipment. The photos help locate areas of abnormal blood vessels and guide the treatment process.

One straightforward method for managing leaking blood vessels is to seal them with a highly focused beam of laser energy. In effect, zapping leaking retinal vessels stops further leaking of material from the vessels, thereby limiting the detrimental effect on vision. When the angiogram identifies discrete areas of leaking vessels, the laser treatments can be confined to these specific areas. This is called *focal treatment*. When the leaking is not due to one or two specific areas, a broader treatment is required.

When the problem of leaking vessels is widespread and excess fluid accumulates in the retinal tissue, it becomes necessary to apply laser treatment scattered over a larger area. This is called *grid treatment* because the laser spots are applied in a grid pattern. This method, like the focal treatment described above, is useful in the treatment of macular edema.

In either situation, the goal of treatment is to stop the vessels damaged by diabetes from continuing to leak and to stop the progression of the visual impairment. Unfortunately, this treatment cannot restore vision that is already lost.

The other, more serious form of diabetic retinopathy, *proliferative retinopathy*, is also treated with a laser. Whereas the treatments in the non-proliferative form are directed at sealing leaking vessels and not destroying tissue, the objective in the treatment of proliferative retinopathy is actually to destroy unhealthy, damaged retinal nerve tissue. To accomplish this, a deeper and larger laser burn is used. This may seem counterproductive to the preservation of vision but the outcome of these destructive treatments does ultimately minimize the cumulative loss of vision. Readers should remember it is the blood- and oxygen-deprived retinal tissue that stimulates the growth of abnormal vessels which never provide any benefit to the retina.

Destroying the unhealthy retinal tissue eliminates the stimulus for the growth of new, abnormal vessels. These abnormal vessels are fragile and can bleed into the interior of the eye, obscuring vision. Patients with proliferative retinopathy may awaken in the morning with new floaters or other visual changes because of bleeding which occurred during the night. Because of rapid eye movements associated with dreaming, these individuals are particularly vulnerable to the breaking of the abnormal vessels during sleep.

Treatment of proliferative retinopathy is accomplished by applying hundreds of destructive spots of laser across much of the peripheral retina. Even though there is relatively widespread treatment, there is very little, if any, sensation of fine visual loss because only the side-viewing retina is treated. Furthermore, the area of the retina being treated is already diseased due to diabetes. Patients may notice a reduction in side vision or night vision and difficulty with light/dark adaptation following this type of treatment. This treatment is called *panretinal photocoagulation* or *PRP*, and usually requires multiple treatment sessions to complete. As mentioned above, laser treatment of proliferative retinopathy is directed at preventing progression of vision loss and does not result in recovery of vision already lost.

Today, new multi-wavelength lasers are available which permit the surgeon to select the most appropriate type of laser beam for the specific problem the patient may have. This flexibility helps the surgeon maximize the beneficial effects while minimizing the detrimental effects of laser treatment.

Another complication of proliferative retinopathy is the formation of scar tissue in the eye associated with the growth of the abnormal vessels. As the scar tissue grows, it may pull on the retina and tear it off of the back of the eye. This is called a *traction retinal detachment* and can be quite severe. A traction retinal detachment may cause severe loss of vision, in some cases ultimately resulting in loss of the eye altogether. Panretinal photocoagulation, by destroying blood- and oxygen-deprived retinal tissue, reduces the stimulus for abnormal blood vessel growth and thereby limits the development of scar tissue. In turn, less scar tissue translates into reduced risk of retinal detachment.

What Other Treatments are Available?

In some cases, bleeding into the eye may occur despite laser treatment. If the amount of bleeding is significant, it can obscure vision.

When this happens, the blood can be surgically removed in the operating room by a retinal surgeon. In addition to removing the blood from within the eye, this surgery has the added benefit of removing the entire jelly-like substance which normally occupies the space in the eye chamber. By removing this substance, the structure into which the abnormal vessels grow is eliminated and therefore, future abnormal growth is quite rare. The jelly-like substance is called the *vitreous*, and the procedure is called a *vitrectomy*. Vitrectomy combined with other microsurgical techniques is also the procedure used to repair traction retinal detachments.

Conclusion

Diabetic eye disease is an important cause of severe vision loss in patients under age 60. However, regular eye exams can detect problems in their early stages. Early detection means that treatment can be started before serious visual loss occurs. All patients with diabetes should have their eyes examined at least once each year, and individuals with more advanced disease may benefit from more frequent evaluations. These exams should be performed by an experienced eye care professional who will dilate the pupils with special eye drops so that the entire retina can be more easily viewed. If laser treatment or other surgery is required, one may then be referred to a retinal specialist.

Through education and cooperation with medical and eye care professionals, the patient with diabetes can remain optimistic about successfully managing the disease and its ocular complications.

A Note on "Brittle" Diabetes

NFB Diabetes Action Network

One of the most prominent features of diabetes is its uniqueness. No two diabetics respond in exactly the same way to food, insulin, or exercise; and no two individuals, even if they show the same test results, will suffer precisely the same ramifications. The disease is, by definition, unpredictable. Still, making allowance for surprises, we know the effects of more insulin, less insulin, more exercise, less exercise, more food, etc.

For most people, most of the time, the "rules" work: "If I do this or do not do that, I can expect this result." But the rules do not seem to apply to some individuals, prompting use of the adjective "brittle" to describe their condition.

The problem becomes separating the truly "brittle" from the non-compliant and the poorly controlled. Some authorities insist that if all diabetics diligently practiced "tight control" (as described by the DCCT), none would be "brittle." They are partially right; the numbers would go down, but some would remain.

Some diabetics, even practicing tight control, find blood glucose level "overreacts" to minute changes in diet, exercise, and/or insulin. These individuals experience unpredictable rises and swoops in blood glucose within very short periods as the result of very small departures from schedule. Small changes "break" their control, and they are thus said to be "brittle."

If a client practices tight control, complies with a schedule, and still experiences rapid, out-of-proportion blood glucose changes, he or she should talk to a doctor. In such cases, their diabetes may be "brittle," but their instabilities may be a sign of some other problem.

PART TWO: SELF-MANAGEMENT

New Dietary Guidelines for Diabetes Management

Mimi Moore, MS, RD

Ms. Moore, a registered dietitian, gave the keynote address at the 1995 annual conference of the Diabetes Action Network of the National Federation of the Blind, from which the following has been adapted. The conference took place on July 3, 1995 at the annual convention of the National Federation of the Blind in Chicago. Although it was directed to an audience of blind diabetics, the editors feel that rehabilitation professionals will definitely benefit from the information provided in this lively presentation.

Diet is very important in the maintenance of quality of life. Progress in science has guided us in making the very best food choices in our daily menu planning. As the saying goes, "You are what you eat." Life span increases as we learn to eat more nutritiously.

What About Diet and Diabetes?

Research results have provided us with some new recommendations for diabetes care and management. Many of you have heard of the Diabetes Control and Complications Trial (DCCT). This was a 10-year project that involved 1,441 participants. Each volunteer was randomly assigned to one of two groups, the conventional treatment group or the intensive treatment group. After 9 years, the study was halted and results given: Complications of diabetes can be prevented or delayed with intensive management.

One year ago, revised nutrition recommendations for diabetes management were issued and supported by the American Diabetes Association (ADA). The emphasis was placed on individualization of care. There is not just one standard plan of management for all type I and type II diabetics.

What is Meant by Intensive Therapy?

Modified care and management has developed through use of the health care team (nurse, dietitian, physician, pharmacist, counselor, and exercise physiologist may all be part of the team). This was one of the main factors in the success of the DCCT. Intensive therapy is now advised for optimal blood glucose control.

Intensifying management means improving control by increasing daily blood glucose checks; using multiple injection therapy; and making continuous adjustments in the coordination of diet, exercise, and insulin or medication. Nutrition therapy is a necessary component in the daily plan for diabetes management.

Long-term dietary goals include:

* maintenance of near normal blood glucose levels;
* achievement of optimal blood lipid levels;
* providing adequate calories for reasonable
weight maintenance, normal growth and

development, pregnancy, and lactation;
* prevention and treatment of acute and long-term nutrition-related complications (hypoglycemia, short-term illness, renal disease, hypertension, cardiac disease); and
* improvement of overall health, incorporating guidelines, and nutrient recommendations for all healthy Americans.

These goals are not accomplished by one single method of meal planning. Traditionally, the meal plan has been conveyed via the Food Exchange System, which provides a good basic foundation for understanding the nutritional principles of diabetes management. Variation in this method occurs with food choices made within each Food Exchange Group. Individualization depends on the amount and type of food eaten. In 1986, the ADA dietary guidelines recommended set nutrient proportions for nutrient composition of the diet: Up to 60% of daily total calories from carbohydrates, 12-20% of daily total calories from protein, and 30% or less of daily total calories from fat.

The 1994 dietary guidelines recommend a shift in nutrient proportions. The distribution of carbohydrates and fat is based on the individual's treatment plan, with no mandatory percentages, and 10-20% of daily total calories from protein.

The ADA position statement (published in *Diabetes Care*, May, 1994) follows research regarding blood sugar response to various sources and types of carbohydrates. The recommendation now states that the emphasis on carbohydrate intake should be on total amount versus type of carbohydrate. The two types of carbohydrate are simple (sugars) and complex (starches and fiber). In the past, we were all advised to avoid foods containing sugar or simple carbohydrates. Now, with scientific evidence for support, we have learned that it is acceptable to have sugar-containing foods as long as they are worked into the daily meal plan and not just added. This liberalization of guidelines has allowed much greater flexibility in day-to-day meal planning.

How Do We Carry Out These Recommendations and Implement Intensified Therapy?

The changes in carbohydrates and dietary guidelines coincide with recommendations for intensive therapy. Continual adjustment is the name of the game--adjusting food to insulin and insulin to food based on blood glucose levels. Greater lifestyle flexibility is an outcome. One is able to eat a meal or exercise "off schedule." Carbohydrate-counting has become a popular method in response to modified therapy.

What is Carbohydrate-Counting?

The focus is on the nutrient carbohydrate because it has the greatest impact on blood glucose levels. The other two energy-yielding nutrients, protein and fat, do not affect blood glucose levels to the same extent. Therefore, attention is placed on the food groups that contain carbohydrates. All foods are made up of a combination of six nutrients: carbohydrates, protein, fat, water, vitamins, and minerals. In turn, all foods are categorized into one of six groups: starches, meats, vegetables, fruit, milk, and fat. Because starch, milk, and fruit are the main carbohydrate-containing groups, they become the focus of meal planning. One Food Exchange portion from each of these food groups equals one carbohydrate serving (15 grams carbohydrate = one carbohydrate serving). This is where knowledge of the Food Exchange System is helpful. A person with diabetes can use the Food Exchange portions for reference.

A specific number of carbohydrate (CHO) servings are assigned to each meal in creating the meal plan. For instance, three CHO servings at breakfast, four CHO servings at lunch, and six CHO servings at dinner may be one person's meal plan. Individualization is key. Every individual's meal plan will be different depending on preferences.

One person may eat two fruit portions and one starch for three CHO servings. Another person may eat two starch portions and one milk for three CHO servings. Suppose you wanted a slice of cake. The food label on a packaged cake says 45 grams carbohydrate per slice. This would equal three CHO servings.

Since the focus is on carbohydrate-containing foods, meat and fat are not counted for CHO servings. But one should not get carried away with portion amounts on these foods! Guidelines are given individually for these food groups.

No restrictions are placed on moderate consumption of vegetables. If one eats large amounts of vegetables, they need to be counted. Three vegetable Food Exchange portions equal one CHO serving.

How Does All This Fit Into the Total Management Routine?

This is where the health care team is needed. Insulin doses are set for the usual carbohydrate serving meal plan. If more carbohydrate than the base plan is desired, more insulin is taken. If less carbohydrate than the base plan is desired, less insulin is taken. Each person's insulin adjustment dose is based on blood glucose values. It takes weeks of testing, record-keeping, and communication with the health care team to establish the appropriate regimen.

I have gone into detail about carbohydrate-counting because it is the method that now seems best matched to intensive insulin therapy. The key is to find a system or routine best suited to a person's lifestyle and preferences, making it easy to maintain optimal blood glucose control.

As a philosopher once said, "Man should eat to live, not live to eat." It's good to know that those times when one wants to live to eat, it is OK. It just takes a few minor adjustments in routine.

Following are questions the audience asked Ms. Moore at the completion of her presentation. They are included here because the answers provide some information useful to the intended audience of this publication.

Q: When you use the term "intensive insulin therapy," what does it mean? Is there a minimum number of shots per day?

A: As per the DCCT, the term means three or more insulin injections per day to be counted as "multiple injection therapy." "Intensifying insulin therapy" could mean going to two shots per day if you currently take only one--then you are "intensifying" it. But when we use the term "intensive insulin therapy," we are talking about pump therapy (where you have continuous injection) or three or more shots per day, and blood glucose monitoring four or more times per day.

Q: What about a type II on just oral medications? What does "intensive therapy" mean for me?

A: As far as the recommendations, these were made for type I diabetics. But we're assuming that they can also be carried over to type IIs because you still need to test frequently to know where your blood sugars are. That's important. You can still adjust your carbohydrate servings, so that's all a part of it. As far as working with your medication, that you need to do with your physician. However, you can still carry through many components of the intensive therapy. It's just that you don't have any insulin to adjust.

Q: Does the ADA have a "recommended renal diet," or is that something to be developed individually between me and my doctor?

A: That's a good question. It's still individualized, but the recommendation that protein be decreased is not as severe as it was in the past. Today, we're saying, for a renal diet, the target should be about

0.8 grams of protein per kilogram of body weight, which is about the American adult recommended amount.

Q: In many situations, people don't get the kind of dietary advice they need, probably because they're on some sort of state Medicaid program. What do you recommend?

A: As far as being able to obtain diet counseling with Medicaid, it is difficult. You could try contacting the ADA as a start. Find out what programs are available in your area. Which are hospital-based? As far as reimbursement, that changes constantly and varies from state to state as to item and amount reimbursed.

For the best results, we need a team approach. We're seeing that education does help curb costs in the long-term. If you're able to take care of yourself, you're able to stay out of the hospital. We need to have more teams to provide better health care. The public health department usually has access to at least one professional, perhaps a nurse educator. There should be a dietitian too. Check with the public health department in your city--that would be a good place to start.

Q: If a check of blood sugar shows it's high, is there any formula for how much insulin physicians think you should take, according to the amount your blood sugar is over the standard?

A: There is no standard formula because it all depends on how you as an individual respond. You might come down a given percent per unit injected, but someone else might need less or more. It's very individualized. You would have to set up a program--establish some kind of scale--in order to know how much insulin to take when your blood sugar is past a certain level. Everybody responds differently, and there is no set answer. And if you as an individual are elevated, perhaps 180, not quite 200 (see below for norms), what you may need is exercise or dietary adjustment; eating less at mealtimes. This holds true for special occasions--times you wish to eat more--as well.

Q: What are the "norms" for blood sugar levels? What are the current recommendations?

A: For people without diabetes, the acceptable range is 60 to 110 mg/dl. For someone with diabetes, we recommend aiming for 70 to 120. Of course, the best range for you depends on your condition. You need to be careful of hypoglycemia, especially if you have cardiac complications. Depending on the individual person, what complications they have, and how active they are, the optimum range may change. With children and infants, it is very hard to detect hypoglycemia, so the ranges may be a little higher. Intensive insulin therapy is not recommended for children with diabetes under 2 years of age.

Q: Those of us with diabetes who are on dialysis face two contrary sets of dietary requirements. When one says, "You can eat this," the other says, "You can't." It is hard to establish an individualized diet plan. Can you explain?

A: The diabetic on dialysis faces the most frustrating of diets because there are so many restrictions on it. You can feel there's nothing you're allowed to eat. There is controversy about what the standards should be. Should protein be kept low? High? No animal protein? Plant only? How many calories? Until we know more about how diet directly impacts renal disease, there will continue to be controversy.

You look at the "macro nutrients"--carbohydrates, proteins, and fat--but you're also looking at minerals too. You've got to go into it in depth and pay close attention to your food types and amounts.

A higher incidence of hypoglycemia is associated with renal disease, and you have to figure that factor into the diet too. Traditionally, health professionals have said, "Treat hypoglycemia with orange juice," but then somebody comes along and says, "No more!", and you have to find something new. That's where it helps to work with the same dietitian, who knows you as an individual, long-term. But do recognize that as renal disease progresses, you will have to make changes in your diet.

Q: You've talked about minerals. Why don't food labels mention potassium or phosphorous content? Where can I get that information?

A: There is a book you can buy entitled, *Food Values of Portions Commonly Used*, 16th ed., 1994, by Bowes and Church. This guide lists all food products with their analysis. If you're on dialysis, you need your own copy. But the food labels don't have that information because the average American doesn't need it.

Another source for the detailed materials you need is available from most dietitians working with renal issues. This is the information commonly called a "renal packet." It is a very difficult diet to follow because there are so many factors you need to coordinate. You may feel you have to follow it exactly, but really you don't. Just work toward some sort of balance each day. [*Editor's Note: The NFB Materials Center in Baltimore has the ADA Food Exchange Lists in Braille or on cassette.*]

Q: Can anybody use an insulin pump? What are its advantages and disadvantages? How does one deal with the risk of infection at the injection site? For diabetics with cardiovascular problems, is an insulin pump a possibility?

A: It should be an option, but the issue needs to be evaluated individually. In some cases, like pregnancy, the insulin pump is recommended because it does a better job of coping with the ups and downs and will provide tighter control. As far as the risk of infection at the pump site, you minimize that by frequent changing of your tubing, your catheter, perhaps more often than the recommended time. Some people are allergic to the adhesive tape used to attach the tubing, but that's another problem.

If you are using the pump, you will need to test your blood sugars four to six times per day minimum. This is important. If you want the pump, you need to commit long-term to the testing. Some people don't like the feel of the pump at night. The insulin pump may not be for everybody. It is individually evaluated. It is one of the recommended ways to institute intensive insulin therapy.

Q: If you are overweight, is there a safe way to lose weight while controlling both diet and insulin? Should I just go to my dietitian for that? Are there other resources?

A: Start with your dietitian. The dietitian may connect you with a counselor who'll help you work on behavior changes, not just food changes. Any changes of this type, you'll want to be long-term. Plan on going "multistep," one step at a time. Set small goals. Lose 4 or 5 pounds at a time--this amount is advantageous!

Q: What if I want some ice cream? How would I "count" it as a carbohydrate?

A: Are you talking about regular or "lite" ice cream? We no longer have just the conventional, high-fat type out there. Today there are also ice milks, frozen yogurts, sorbets, and sherbet. All have varying degrees of fat.

If you really want that premium ice cream, what will you leave out of your diet to balance all that fat? You have to exchange! For one half cup, you have to exchange one bread but also two or three fat servings. Somewhere in your meal plan you can eat less meat, so as to leave out some of that fat. If you want more for your dollar, have the sorbet instead, and leave off just a few pieces of bread. Sorbet is nonfat. And remember: Just because something is "fat-free" doesn't mean it is calorie-free or sugar-free! Even ice cream made with NutraSweet or sorbitol can be high in carbohydrate, especially if it has a milk base.

Still another trap is "no sugar added", or "sugar-free". They contain carbohydrates because fruit has been added for sweetening. Sometimes the fruit-sweetened product contains more carbohydrates than does the sugar-sweetened one. Look at the total carbohydrate content on the label.

Q: When I look at a box of cereal, I see listed: "Total carbohydrates, complex sugars, dietary fiber, and other carbohydrates." With the new guidelines, what should I be looking at?

A: Cereal is a hard product to work with. There is so much variability, and the different cereals have different serving sizes. One half cup of one cereal may contain the same amount of carbohydrates as one third cup of another. I would start by looking at the serving size. If I want to eat a big bowlful, I'll look for a flake cereal. Next, I would look at fiber content. If I want high fiber, I will choose bran, wheat, or oats because the corn flakes or rice krispies don't have a high fiber content.

As far as the new recommendations, what we're saying is that the total amount of carbohydrate is what matters more than what kind. If you want frosted sugar flakes, go for it, but then look at what your total carbohydrate serving is. That is more important to focus on than the sugar. If there are 36 grams of carbohydrates in a one half cup portion, that's going to count for two servings of carbohydrates. Look at the total amount of carbohydrates per serving. I would also look at fiber content and serving size.

Q: How do I know if there's sugar in my food?

A: Dextrose, fructose, lactose, corn syrup, and honey. . . are all sugars. If it ends in "--ose," it's a sugar. All simple sugars have the same calorie content per gram. With the old recommendations, when we used to watch out for different types of sugars, we had so much more to sift through. Was it corn syrup or was it fructose?

Now, with the new recommendations, we are saying the type of sugar doesn't matter--you need to look at the total amount. There may be corn syrup in one product, fructose in another, but 15 grams of carbohydrate will react the same, no matter what form it takes.

Q: How much carbohydrate per day should a person have? And what kind? If too much of the total comes from sugar, won't that burn off quickly and cause reactions?

A: We used to say that up to 60% of a person's total caloric intake should come from carbohydrates. Now, we look at the individual. There are a lot of "if's" about total amount.

When you're looking at carbohydrate intake, it doesn't matter about the source. If you have 30 grams, as far as its impact on your blood sugar, it doesn't matter whether it comes from sugar or starch. If you eat a mixed, balanced meal and stay on your program, you are at no greater risk for reactions than before. In fact, compared to fats and proteins, carbohydrates are the fastest to be metabolized.

Q: Can you talk about sodium? How much should we have per day?

A: As you eat more salt, you crave more salt. The average American probably consumes 6,000 mg per day. We recommend that a healthy American consume 2,400 to 3,000 mg of sodium per day; 2,400 mg, a "low sodium diet," is what diabetics should aim for.

The more processed foods you eat, the more salt you are consuming. Convenience foods, fast foods, or anything processed usually has salt or sugar added. These alone can probably take you to the 6,000 mg mark.

Q: I've been told intensive insulin therapy won't work for me because I have "hypoglycemia unawareness." Is that right?

A: You have to do what is appropriate and safe for you. What we call "full-blown intensive therapy," with its increased risk of hypoglycemic episodes, may not be appropriate in your case. Perhaps you can intensify, improve your control, without going as far. Keep those blood sugars under the best possible control. [*Editor's Note: One reviewer noted that if one is hypertensive, the goal should be less than 2,400 mg/day.*]

Review of Oral Diabetes Medications

Peter J. Nebergall, Ph.D.

Currently, there are an estimated 16 million diabetics in the United States. Perhaps 10% are insulin-dependent; the rest have type II diabetes, controlling their condition with diet, exercise, and oral medications.

Oral medications are not insulin pills; rather, four classes of drugs designed to improve the body's utilization of what insulin is still present. These are: the *sulfonylureas*, *metformin*, *troglitazone*, and *acarbose*.

Most "diabetes pills" are sulfonylureas, a class of chemicals that stimulate the pancreas to produce more insulin, effectively lowering blood glucose levels. Type II diabetics, those who need better management than diet and exercise can provide, often turn to these medications: *tolbutamide*, *chlorpropamide*, *tolazamide*, *glyburide*, *glipizide*, and new *glimepiride* for effective self-management. The *sulfonylureas* are effective, but only so long as the pancreas maintains some of its insulin-making capacity.

But the sulfonylureas grow ever less effective with the passage of time. They drive the failing pancreas to greater effort, but the patient may well require ever-increasing doses. At some point, no further increase in medication will be effective; the pancreas isn't doing its job, and the patient needs to start injecting insulin. When the islet cells of the pancreas stop making sufficient insulin, insulin must be injected.

Metformin, the second of the oral diabetes medications, works to raise the body's sensitivity to its own insulin. Used for decades in Europe, it can be prescribed alone or with the sulfonylureas. Metformin helps the type II diabetic make better use of the insulin he or she has left. Like the sulfonylureas, it becomes useless when the pancreas ceases producing adequate insulin.

Troglitazone (trade name *Rezulin*, from Parke-Davis) is the third oral medication. Rezulin directly attacks the problem of insulin resistance, the increasing inability to process insulin, that is the chief component of type II diabetes. Intended for insulin-using type II diabetics, Rezulin enabled many to reduce volume and frequency of insulin injections. A few were able to discontinue insulin injection entirely.

As with other oral diabetes medications, Rezulin's effectiveness depends on the **presence of insulin**. If sufficient insulin is not present, it **must be injected**, and Rezulin therapy will not change that fact. Where insulin *supply* rather than insulin *resistance* is the issue, Rezulin therapy offers nothing.

As per who may benefit from use of this medication, Parke-Davis states:

> "Rezulin is indicated for use in patients with type II diabetes [who are] currently on insulin therapy, and whose hyperglycemia is inadequately controlled (HBA1C > 8.5%) despite insulin therapy of over 30 units per day, given as multiple injections...Rezulin should not be used in type I diabetes or for the treatment of diabetic ketoacidosis."

Published data state that, although degree of renal insufficiency has no effect on Rezulin dosage, persons with hepatic (liver) disease should exercise caution. Other data suggest that, in premenopausal anovulatory women, Rezulin therapy may result in resumption of ovulation, and risk of pregnancy. There is further recommendation to proceed with caution if the individual is taking antirejection drugs such as *cyclosporine* or *tacrolimus*.

Acarbose, the fourth of the current "oral meds", is completely different. A *carbohydrase inhibitor*, it temporarily suppresses the digestive enzymes which turn carbohydrates into glucose, slowing digestion and glucose absorption, keeping glucose levels more even. More a management tool than an antidote to insulin shortage, acarbose helps some diabetics keep a more constant blood glucose level. A "temperamental" medication, it has many side effects, and is less than universal in its utility.

Problems

Unfortunately, oral medications are often eventually insufficient. Many type II diabetics, diagnosed as young adults, at first successfully control their condition with diet and exercise but find they need the pills as they grow older. A number of years (and dosage increases) later, these diabetics have reached the limit of what oral medications can do for them; they are "maxed out" and really need to start injecting insulin. (Note: Regular, frequent blood glucose monitoring will show if they have reached the point where they should begin insulin therapy.)

Here we encounter what the drug companies call "psychological insulin resistance." Some of this is plain old fear of sticking oneself with needles--nurtured by memories from our childhood in the bad old days of dull-as-nails reusable syringes. Many otherwise brave men would rather face a bayonet. But some doctors contribute to the problem when they don't make clear to the patient what the high glucose levels consequent to remaining on now-useless oral medications will bring in their wake. Yes, insulin is a powerful medication with risks if used incorrectly--but what in this world DOESN'T have risks if used incorrectly? The risks of remaining on oral diabetes medications once pancreatic insulin has diminished or ceased entirely are far greater than the risks of taking insulin.

Oral Insulation

Recent reports have mentioned insulin administration by mouth. The nature of insulin, and human digestion, make oral administration of insulin ineffective for blood glucose management--the insulin is digested before it can reach the bloodstream. The oral insulin administration here noted is taking place as part of several diabetic prevention trials. In one example, individuals considered at high risk for developing diabetes (but not yet "diabetic") are given oral insulin in an effort to misdirect their body's autoimmune attack on the Beta cells of the pancreas. Oral insulin, very "investigational" at this time, is not currently an option for blood glucose management.

The Future

Researchers at Johns Hopkins University are testing *aminoguanidine*, a new medication that may prevent or reduce some of the ramifications of diabetes. Swedish and American researchers are testing still another (APO A1 MILANO, covered in *Voice* Vol. 10, No. 4) that may help reduce diabetic heart disease. Aerosol spray insulin (for nasal administration) is being tested, and may someday supplant injection. *Trental* (*pentoxifyline*, from Hoechst Marion Roussel) is now available to treat "intermittent claudication", a painful circulatory ailment and frequent companion of peripheral neuropathy. ACE inhibitors, a class of blood pressure medications like Capoten (captopril), have been proven to deter and retard diabetic kidney complications. Other oral medications are constantly being evaluated for possible diabetic applications. Change is coming quickly.

Diabetes and Exercise

NFB Diabetes Action Network

The image of the muscular athlete bathed in sweat, receiving the gold medal, is deceptive. Exercise, the pursuit of physical fitness, is not just for Olympians and professionals. The ancient Greek physician Hippocrates of Kos taught that a well-balanced lifestyle, with proper diet and appropriate exercise, was good therapy.

But we seem to have lost something since that time. In our worship of convenience and pursuit of the latest technology, we forget that sometimes the old ways were good for people. Almost nobody gets enough exercise these days, but this deficit is more critical for the diabetic.

Whether a person has insulin-dependent or non-insulin-dependent diabetes (IDDM or NIDDM, type I or type II), the end result is an oversupply of undigested glucose in the blood. This leads to hyperglycemia and opens the door to a whole host of serious, possibly life-threatening complications. Good diabetes control consists of getting blood glucose numbers down into the safe range and keeping them there.

Exercise burns blood glucose. It is so effective that, coupled with proper diet, it forms the basis for certain types of diabetes therapy--the "diet and exercise" regimes followed by many type II diabetics. But exercise is not just for these people.

No matter what type or degree of diabetes one has, regular physical exercise helps protect against hyperglycemia and ramifications, possibly lessening the need for insulin and/or oral medications. To the degree that it leads to weight loss and to maintenance of ideal weight, it can cut insulin resistance, leading to a reduction in the need for medication. It lowers blood cholesterol, reducing the risk of heart complications, and it cuts stress, keeping down the adrenalin level and improving diabetes control. Are these not reasons enough?

Many people act as if exercise requires one to be fit before beginning it, as if the benefits must precede the act. "Oh, I can't do that; I'm not in shape." This belief is unfounded. Regardless of level of fitness, and regardless of ramifications, a program of regular physical exercise will be of benefit. Diabetics considering exercise programs should talk to their doctors; then they and their health care teams can plan realistic programs appropriate for them.

What can those interested in getting started do? Although a lucky few get to work out in well-equipped gyms, they are not a requirement. Walking with dog or cane is high-quality exercise, and requires only a route to follow and the motivation to do so. Swimming provides a full-body workout while minimizing "impact," repetitive stress to the joints. Those in manual wheelchairs already know what a quality workout that device can provide. Electric wheelchairs merely require a little more creativity. A variety of home exercise equipment is available: treadmills, exercise bikes, rowing machines, and lifting machines. Individual circumstances may make one or more of these appropriate.

Good exercise regimes are as varied as the people who follow them. A number of exercise physiologists have workout routines for people who must remain seated while exercising, and the health care team should be aware of them. Several are available as videocassettes. Exercise for those in chairs or after an amputation should present no more challenge than does getting dressed.

There is one special consideration for those with diabetes who exercise. Since exercise burns glucose, hypoglycemia--low blood sugar--becomes a possibility. Diabetes is a balancing act between too high and too low, and exercise drops the numbers. One should take a glucose monitor along and test before starting exercise. Those results, and perhaps another test part way through a prolonged workout, can determine if one needs a snack. Testing again after exercise is advisable.

As people learn their individual responses to specific types and amounts of exercise, they can better balance food and insulin intake. If they take along a source of quick sugar (glucose tablets, orange juice, lifesavers, cake-icing, etc.), they should be able to respond immediately to steep drops in blood glucose and keep themselves out of danger. They must remember to talk to their doctors about adjustment of insulin dosage.

The ability to "feel" an oncoming insulin reaction varies from person to person. Some have little problem; when they feel "shaky," they have a snack. Others have greater or lesser degrees of "hypoglycemia unawareness," the inability to feel an oncoming "low." For these individuals, especially those who can't detect a low until they are almost unconscious, frequent glucose monitoring, rigid attention to schedule, and perhaps "buddy system" exercise can provide the needed margin of safety.

There are other ways to improve safety. Wearing properly fitted athletic shoes of good quality, with appropriate athletic socks, should be prerequisite to walking or jogging. Afterwards, feet should be checked for blisters, bruises, or any other damage. Working out in public should include wearing appropriate medical identification and, if there is any doubt about visibility to passing drivers, wearing bright clothes. Exercisers should remember to give themselves warm-ups before and cool-downs after a workout. Having an exercise partner is a good idea--it also spurs motivation!

The word ***exercise*** comes from an old Latin word meaning "training." The Romans knew that to have value, an exercise program had to be disciplined, with regular actions and on a regular schedule. Once people have established workout routines, they should follow them, conferring first with their health care teams and then setting realistic goals and sticking with them.

[*Editor's Note: One reviewer recommends that exercise not be undertaken when blood sugars are above 300 mg/dl. She also urges avoidance of exercises like weight-lifting and other jarring activities by those with retinopathies, nephropathy, and neuropathies, and discourages other forms of exercise resulting in rapid changes of blood pressure.*]

About Insulin

NFB Diabetes Action Network

Newly-diagnosed diabetics have many questions, like: What is this stuff I have to take? Is it a drug? Will it make me better so I don't have to take it anymore? What does it do? Why can't I just drink it or take a big shot once a month? And why are there so many different types? Will there ever be something better?

Insulin is a hormone normally produced in sufficient amounts by the healthy pancreas. Its role is to facilitate the final digestion of glucose by the body. When insulin is lacking (as in the case of diabetes), glucose remains undigested in the blood. The body isn't being fed, and the high blood sugar can cause damage, the ramifications of diabetes.

The two major types of diabetes (type I and type II, IDDM and NIDDM) are separated by presence of insulin. The pancreas of the type I patient has ceased producing insulin, and insulin must be injected. This injected insulin is a replacement and, barring the transplantation of a healthy pancreas, will need to be continued for life.

The type II (NIDDM) patient has an impaired insulin supply. He or she doesn't have enough or has some difficulty assimilating it (insulin resistance) or experiences both conditions. Lifestyle and diet changes, along with oral medications, some of which stimulate the failing pancreas to produce more insulin, are used in treatment. Many individuals with type II diabetes find their insulin supply, already impaired, has lessened to the point at which they need to inject insulin.

Insulin cannot be taken by mouth because it is digestible. Oral insulin would be obliterated in the stomach, long before it reached the bloodstream where it is needed. Once injected, it starts to work and is used up in a matter of hours. Depending on a number of factors, individuals vary insulin volume, type, and frequency to optimize blood glucose management.

The existence of so many different formulations of insulin is partly intentional and partly an accident of history. Before insulin, individuals with diabetes just died. When the hormone became available in the 1920s, doctors realized patients' needs differed. As newer formulations of insulin became available, it was discovered that the best blood sugar control was achieved by use of a mix of insulins of different duration and time of onset (as described below). The earliest insulins were made from animals ("animal-source") but newer types are made "in the test tube" ("recombinant DNA origin"). The existence of so many different insulins helps the doctor tailor a dosage best for a specific individual. As new types of insulin are invented, they will help achieve an even better "fit."

Many patients have specific questions about insulin use. Some of the most common are listed below:

Q: How long before a meal should insulin be injected?

A: With "Regular" insulin, it is recommended that one inject 30 minutes before meals. With Humalog (Eli Lilly & Company's trade name for quick-acting Lispro insulin analog), a 10-minute wait is sufficient. Insulin works far better when given sufficient time to do its job. Diabetes self-management requires keeping to the established schedule. Too much time or too little will cause problems. Waiting after injection for blood glucose to drop before starting to eat may limit the "glycemic excursion" (blood sugar rise) that follows a meal, but this approach means taking chances with possible hypoglycemia.

Q: Do insulin absorption rates vary from one person to another?

A: Yes. Some individuals get 16-20 hours out of an NPH/Lente shot, while others get 8-12 hours. One can experience day-to-day variation of up to 50% with the same dose. The same person, with the same dose and technique, may also see a day-to-day variation of 25-50% in time of insulin peak action.

Q: Does exercise affect absorption?

A: Yes. Exercise of a given muscle area after injection of insulin into that area will cause the insulin to be absorbed faster. Exercise, in general, burns up blood glucose, lessening the need for insulin to digest it and thus increasing the effect of injected insulin. Massage of the injection site after injection can help speed absorption.

Q: Which injection technique makes the insulin work faster--Subcutaneous or Intramuscular?

A: Intramuscular (IM) injection is faster. However, IM injection is not for regular use and has its risks. A doctor may use it in special situations, but day-to-day insulin injections should all be of the subcutaneous (SubQ) type. Mixing the two would inject another variable into diabetes control.

Q: Does being a smoker change insulin absorption?

A: Yes. Along with all the other damage it does, smoking decreases insulin absorption.

Q: What are the absorption differences between insulin injection sites?

A: The abdomen is the fastest, followed by arms and thighs (no data available on absorption rate in the buttocks). These differences may be used to prolong or speed up the effect of insulin for special circumstances, but it is best to keep injecting within one anatomical area for consistency in time of onset.

Q: Does the speed with which I push the plunger of the syringe make any difference?

A: No, velocity does not make any difference.

Q: Does the angle of injection make any difference in absorption?

A: The angle of injection (45 to 90 degrees) makes no difference, although some suggest that it may in cases of extreme obesity.

Q: Does skinfold thickness affect absorption?

A: The more fat present in the injection site, the slower the absorption.

Q: I want to switch from animal-source to human insulin. Is there much difference?

A: Human (recombinant DNA) insulins work faster than animal-source insulins of the same type, so you may need to recompute your daily doses. Talk to your doctor.

Q: Why is "rolling" the insulin vial before drawing up a shot preferable to shaking it?

A: The recommendation is to roll only the suspension insulins, NPH and Lente. There is no need to agitate Regular insulin. Shaking instead of rolling the vial would produce air bubbles.

Q: How should insulin be stored?

A: Insulin vials should be kept refrigerated until you are ready to start using them. Then they need to be kept in a cool place, away from extremes of temperature. Insulin is fragile, and exposure to extreme heat or freezing can destroy its efficacy.

Q: How can I have a more flexible insulin regimen?

A: Some people use sliding scales and algorithms for the regular dose, according to the amount of food taken at the time. Use of such a technique requires thorough familiarity with its details.

Q: What is "buffered" insulin?

A: Buffered Regular insulin is for use in insulin pumps. It acts just like other "R" insulins but contains a buffering agent to make it more stable for such use. Some people use conventional, unbuffered Regular in their pumps, but the manufacturers recommend use of the buffered variety.

Q: What are the durations and peak times for the different insulin classes?

A: The following chart is from *Stop the Rollercoaster* by Walsh and Roberts, with further data provided by Eli Lilly & Company. Note that times are approximate, and will vary between individuals. Many of the data in the body of the article were compiled by Arturo Rolla, M.D. of Harvard University, School of Medicine.

Insulin	Start	Peak	End	Lows most likely @
Lispro	10 min	1 hr	4 hr	2-4 hr
Regular	20 min	3-4 hr	8 hr	3-7 hr
NPH	1.5 hr	4-10 hr	22 hr	6-13 hr
Lente	2.5 hr	6-12 hr	24 hr	7-14 hr
Ultralente	4 hr	10-18 hr	36 hr	10-22 hr

Insulin Measurement Devices

NFB Diabetes Action Network

[*Editor's Note: In articles which follow, including this one, the reader will be given information on specific aids and appliances. Although including this material, the editors intend no explicit or implicit endorsement of specific products.*]

Most diabetics, blind or sighted, want and need to achieve control--

independent self-management--of their diabetes. But if one cannot rely on vision to measure insulin accurately, he or she MUST have effective alternative techniques specifically designed for individuals with partial or complete vision loss. Many manufacturers have risen to the occasion; with the appropriate adaptive equipment, non-sighted self-management is a reality. Each person's abilities (and ramifications) vary, and it is important to remember that different devices best meet different needs.

Some diabetics with fluctuating vision will find that at certain times of the day, they can rely on their vision to measure insulin accurately. At other times, their visual acuity may diminish, leaving them guessing at the dose of insulin or relying on sighted aid. The eye condition of a person with diabetes can change daily, making reliance on visual techniques unsafe.

The following is a catalog of alternative devices for insulin measurement. Some are designed for those with partial sight. Others are intended for non-visual operation. A few are the simplest of home-made aids, designed by resourceful individuals with diabetes who are blind, some of whom are members of the Diabetes Action Network. [*Note:* Prices quoted do not include shipping charges.]

Insulin Measurement Systems

The Count-A-Dose: This insulin measuring device is manufactured by Jordan Medical Enterprises, 12555 Garden Grove Blvd., Suite 507, Garden Grove, CA 92643; telephone (800) 541-1193.

Cassette instructions are supplied. Its suggested retail price is $49.95, although the NFB sells it for $40. *(The reader will find information on vendors in the Appendix.)*

Designed for the Becton Dickinson (B-D) .5cc LoDose (50-unit) syringe, the Count-A-Dose holds two insulin vials and directs the syringe needle into the vials' rubber stoppers. The user can easily mix two different insulins, and the "T-bar" that holds the vials has clear and obvious tactile marks to aid insulin differentiation. Dose size is adjusted with the thumb-wheel, which clicks for each unit measured (clicks can be both heard and felt) up to 50 units. The device provides easy, reliable, and accurate non-sighted insulin measurement.

[NOTE: The NFB Materials Center has a supply of the older, now discontinued, 1cc/100-unit Count-A-Dose. Operation is similar, but this device uses the B-D 100-unit syringe, and each click of the thumb-wheel draws 2 units. No audio instructions. Price is $40.]

The Syringe Support: This device is manufactured in Canada by the Foundation Centre Louis-Hebert, 525 Boulevard Hamel Est, Aile J, Quebec City, (Quebec) Canada G1M 2S8; telephone (418) 529-6991. Instructions (standard print only) are bilingual. In the U.S., the Syringe Support may be purchased (cost $19.95) through Lighthouse Consumer Products, 36-02 Northern Blvd., Long Island City, NY 11101-1614; telephone (800) 829-0500.

The Syringe Support uses only the B-D 1cc/100-unit disposable syringe and measures insulin in 1- or 2-unit increments, in doses of 1 to

100 units. To mix insulins with the device, it is necessary to remove vials from the apparatus. To draw a measured dose, the Syringe Support depends on a set screw with a raised flange, its only landmark, at 12 o'clock. One full turn draws 2 units. One half-turn draws a single unit. Although the dial lacks definite tactile or audio indicators, in most cases, any error would be fractional. Still, the Syringe Support performs best for those who must draw doses of greater than 10 units.

The Load-Matic: This device is available for $49.95 from Palco Labs, Inc., 1595 Soquel Drive, Santa Cruz, CA 95065; telephone: (800) 346-4488. This device allows two different measurement increments: 10-unit and/or single units of insulin. It uses only 1cc/100-unit B-D syringes. Depressing the lever measures a 10-unit increment, and turning the dial one click measures a single unit. To mix insulins with the Load-Matic, as with the Syringe Support, it is necessary to remove and replace insulin vials from the device.

Although an intriguing design, the Load-Matic features an overly complex operating drill, with many opportunities for user error. Ambiguous and incomplete instructions take a high degree of familiarity for granted and may confuse the inexperienced. Its 10-unit lever, if incompletely depressed, is capable of dispensing the unwary user an incorrect dose. The Load-Matic's cassette instructions tell the blind user to draw only about 700 units out of an insulin vial with the device since "this assures that you will never draw air into your syringe instead of insulin." The printed instructions lack this statement. The instructions make no provision for removing air bubbles from the syringe, which can easily be accomplished by drawing 4 or 5 units of insulin, reinjecting them into the vial three times, and drawing the full measured dose the fourth time. Insulin mixers need to do this only with their Regular insulin, the first they draw.

Home-made Insulin Measurement Gauges

The simplest insulin gauges are devices which allow the plunger on an insulin syringe to descend a set distance and no more. The distance corresponds to a measured dose of insulin; the gauge enables that dose to be reliably duplicated without sight. To draw a different dose, the user must use a different gauge and thus may need quite a collection. Gauges may be of a number of shapes (flat, corner-molding, tube, etc.) and can be constructed of many different materials (wood, plastic, metal, old credit cards, etc.), but most of them are rigid, flat, and several inches square. On one end of the gauge is an L-shaped notch. This L-notch fits on the plastic collar located between the flanges and the plunger of the insulin syringe.

Further down the insulin gauge is the small slot where the plunger seats, once the correct dose for that particular gauge has been reached. An insulin gauge should be made to keep the slot very narrow to insure that when the plunger is seated in the slot, there is no play (which would allow a variation in the dose). The L-notch and the slot must both be on the same side of the insulin gauge.

Although many people make their own insulin gauges out of all types of materials, commercial gauges are available. Meditec, Inc., 3322 S. Oneida Way, Denver, CO 80224; telephone (303) 758-6978, offers Insulgages, flat plastic gauges analogous to the home-made types described above but labeled in Braille with raised numbers. Priced at $9.75 each, these are cut for either B-D or Monoject syringes, and many sizes are available, one insulgage per dose. Use of insulgages in conjunction with the Holdease needle guide and syringe/vial holder (also sold by Meditec at a cost of $12.75) enables non-sighted insulin measurement.

The best insulin gauges, home-made or commercial, are made from the most durable materials available. Insulin gauges constructed from cardboard or staples, however inexpensive, are NOT RECOMMENDED. They distort and break too easily.

Help with constructing an insulin gauge can be obtained from the Diabetes Action Network. A more complex home-made insulin measuring device was designed years ago by *Voice* editor Ed Bryant. His gauge was a carefully carved block of wood that allowed precise syringe placement, non-sighted insertion of needle into vial, and reliable tactile duplication of preset doses. To change the dose, he had only to replace one wooden or plastic preset with another. It worked well, but he feels that, since most people do not have access to the necessary precision woodworking, they would be better served by the Count-A-Dose, which he now uses. *(Note: The use of non-standard or home-made insulin-*

measuring devices should only follow a thorough check of such devices.)

It is important to understand that insulin gauges are "cut" for a specific brand and size of syringe. Therefore, an insulin gauge that has been cut for a Monoject, Terumo, or other type syringe cannot be used and will not produce an accurate reading on a B-D syringe and vice versa. An insulin gauge cut for a 1cc B-D syringe cannot be successfully used on the 0.5 cc (Lo-Dose) or 30-unit B-D syringe for the same reason.

Appliances and Holders

The Insulcap, a color-coded, tactile-cue-equipped plastic fitting, attaches to an insulin vial and guides insertion of the syringe, holding the needle at the correct depth. The syringe won't shift and bend the needle since the Insulcap holds the bottle to the syringe, freeing both hands for the filling operation. Offered by Diabetic Insulcap, Inc., P.O. Box 34347, Las Vegas, NV 89133-4347; telephone (702) 363-0426, the Insulcap is sold in sets of two: one blue, without tactile cues and one orange, with tactile cues. Suggested retail price is $7.95. Individuals with low vision, arthritis, or other conditions causing unsteadiness may benefit, though those without sight would be better served by devices such as the Count-A-Dose.

The Inject-Aid is a syringe/vial holder incorporating a preset that allows consistent non-sighted drawing of a set, pre-determined insulin dose. Note that insulin *adjustment* requires sighted aid. The Inject-Aid costs $7.95 and is available from George Wright Industries, 3741

Faulkner Drive, Apt. 301, Lincoln, NE 68516; telephone (402) 423-3253.

The Uni-Cal-Aid is similar to the Inject-Aid but incorporates two adjustable preset stoppers, allowing two different doses or insulin mixing. It accepts all syringe types but any adjustment of dose requires sighted aid. Price $25 U.S. or $30 Canadian, available from Uni-Cal-Aid, P.O. Box 1000, Hope, B.C., Canada V0X 1L0; telephone (604) 869-5648.

Pen Injection Devices

The Novolin Pens. Novo-Nordisk Pharmaceuticals, Inc., 100 Overlook Center, Suite 200, Princeton, NJ 08540; telephone (800) 727-6500, produces 3 pen-type devices. They offer the "Novolin Pen," which retails at $40 (excluding insulin cartridge) and uses 150-unit "Novolin System" insulin cartridges (R, N, or 70/30 mix) and "Penneedle" replacement needles. This device delivers a measured dose of between 2 and 38 units, in 2-unit increments. Novo-Nordisk also offers "Novolin Prefilled" disposable syringes. These devices are smaller than a pen injector, hold 150 units of R, N, or 70/30 mix insulin, and are packed five syringes per package; suggested retail price is (package of five syringes) $19.10, comparable to the cost of cartridge replacements for the Novolin Pen.

Novo Nordisk has a new pen injection device, the "Novo Pen 1.5." Similar to the Novolin pens, it uses the 150-unit Novolin insulin cartridges, and delivers insulin in 1-unit increments. According to the manufacturer of the Novo-Nordisk pens and the prefilled Novolin syringes, none of their devices are recommended for use by blind or visually impaired persons without sighted aid.

The Autopen is a British-made insulin pen injector designed to use the Novolin system cartridges and disposable needles. In the U.S., it is marketed by Owen Mumford, Inc., 849 Pickens Industrial Drive, Suite 12, Marietta, GA 30062; telephone (800) 421-6936. It is available in two versions: a 1-unit increment (administers up to 16 units) and a 2-unit increment (up to 32 units) pen, differentiated only by color. Each is priced at $33.50.

Becton Dickinson Corporation and Eli Lilly and Company offer, as a joint venture, the Humulin Cartridge System pen insulin injection system, the B-D Pen. Similar to the Novo Nordisk and Mumford pens, the system dispenses 150 units of R, N, Humalog, or 70/30 insulin, in 1-unit increments, from 1 to 59 units.

Syringe Magnifiers

The Insul-Eze 6000, manufactured by Palco Labs (listed above) is a syringe-and-vial holder incorporating a full-length 2x lens, allowing the insulin-drawing operation to be closely monitored. Insulin vials can be changed for mixing without disturbing the syringe. Adaptable, the Insul-Eze works with most types of syringes in the 30-, 50-, and 100-unit size. Cost: $11.

The Truhand, a device similar to the Insul-Eze, is offered by Whittier Medical, Inc., 865 Turnpike Street, North Andover, MA 01845;

telephone (800) 645-1115. It allows use of different syringe types and sizes and firmly holds the vial, while providing a 3x magnified view of the scale. Vials can be changed for mixing without disturbing the syringe. Cost: $29.95.

The Magniguide is offered by Becton Dickinson Consumer Products, One Becton Drive, Franklin Lakes, NJ 07417-1883; telephone (800) 237-4554. It attaches to the insulin vial and provides 2.5x magnification to aid needle insertion, precise dose measurement, and location of bubbles in the syringe. The Magniguide is available (cost: $3.95) from Independent Living Aids, Inc., 27 East Mall, Plainview, NJ 11803-4404; telephone (800) 537-2118.

The Ezy-Dose Syringe Magnifier fits all .5cc and 1cc syringes and clips to the syringe barrel, magnifying the scale 2x to aid precise dose measurement. Manufactured by Apothecary Products, Inc., 11531 Rupp Drive, Burnsville, MN 55337-1295; telephone (800) 328-2742, the device does not affect needle insertion, which must be done visually. Price: $4.95, available from LS&S Group, Inc., P.O. Box 673, Northbrook, IL 60065; telephone (800) 468-4789.

The Cemco Syringe Magnifier, available in three sizes (to fit syringes of 1cc, .5cc, and .33cc), is offered by Cemco, P.O. Box 31, Scandia, MN 55073; telephone (612) 433-3374. The magnifier clips to the syringe and aids precise filling but needle insertion into the vial must be done visually. Price: $5 retail, or $42 per dozen (any combination of sizes).

The Diabetes Action Network of the NFB is a support and information network for all diabetics. We have many members willing to share their expertise in non-sighted techniques of diabetes self-management. Anyone with questions about diabetes and blindness, should feel free to contact the Network and the other organizations at the addresses which appear in the Appendix.

Blind Diabetics Can Draw Insulin Without Difficulty

Ed Bryant

A major aim of the Diabetes Action Network of the NFB and many other organizations is to provide support and information for blind diabetics so they might better maintain or regain independence and productivity. National support and information networks allow communication across a wide area, something important for individuals with diabetes who are blind or visually impaired and their families. With the trauma of sight loss, sometimes the newly blinded do not realize that most men and women who are blind as a result of diabetes CAN manage safely and accurately themselves through use of alternative techniques.

I became blind from diabetic retinopathy about 17 years ago. When I first lost sight, I didn't use insulin gauges to help draw my insulin since I had never heard of such devices. Fourteen years ago, I designed my own insulin gauge, and I used it for approximately 3 years with no difficulties. I do not advocate the use of nonstandard or home-made insulin-measuring devices unless they have been checked out by someone knowledgeable in insulin-measuring techniques.

Members of the health care community sometimes forget that, although a diabetic may be newly blinded, he or she has often been successfully self-managing the disease for 15 years or more. Most who have had type I a long time have had years of experience drawing their own insulin. Veteran blind diabetics often have more experience with adaptive insulin preparation devices than do many sighted health professionals. The following observations are only a small sample.

Because of my experience with diabetes and blindness and my editorship of *Voice of the Diabetic*, I am often asked to evaluate insulin-measuring gauges designed for people who are blind or visually impaired. I have tested numerous measuring devices, and in my opinion, the Count-A-Dose from Jordan Medical Enterprises is suitable for a broad range of users. I hasten to add that no one instrument is ideal for everyone; however, the Count-A-Dose provides a very easy method of insulin dispensing.

How to Get Air Bubbles Out of an Insulin Syringe

There are techniques by which a person who is blind may draw and mix insulin without drawing air into the syringe. Like many others, I have used them successfully for years. I first draw 4 or 5 units of Regular insulin into the syringe and then inject all of it back into the vial. I then repeat the operation two more times. The fourth time, I draw the full amount of insulin needed from the first vial. Then, when I draw insulin from the second vial, I draw the exact amount needed. I have put this to the test; 100 repetitions without air bubbles. Diabetes Action Network Second Vice-President Janet Lee has twice performed the same test. In both cases, the complete absence of air in the syringe was independently verified.

"Tapping the syringe to remove air bubbles," a common technique used by the sighted, becomes unnecessary. The 1 to 2 units of air in the hub of the needle (where needle meets syringe) are expelled during the procedure used with the first vial of insulin. I demonstrate this technique to nurses who are delighted to see that air bubbles are not present and the insulin measurement is accurate. Of course, long-term insulin users will be familiar with the need to inject as much air into the vial as the amount of insulin they withdraw, to facilitate getting the insulin into the syringe. For further information, users should consult their health care teams.

How to Know When an Insulin Vial is Getting Low

Each vial of insulin contains 10cc, 1,000 units. The maximum number of units used per day, divided into the vial's 10cc (1,000 units) capacity, gives the maximum number of days the bottle can be used. When I open a new vial of Regular insulin, I divide its 1,000 units by 20 units, the maximum I use daily, so one supply should last me 50 days. As a safeguard, I assume that the new bottle contains only 940 units (9.4cc), which should last a maximum of 47 days instead of 50. I measure my

NPH insulin in a similar manner. As long as at least 60 units of insulin remain in the vial, the needle will remain submerged while filling, and there is no danger of drawing air. In drawing out the insulin, I keep the syringe vertical, needle straight up in the vial, so as not to draw out air inadvertently. Many consumers who are blind (and diabetes educators) are unaware of this point's importance--that the natural tendency is to tilt or slant while drawing, which can lead to inaccurate filling and air in the syringe.

Many methods exist to determine how long a supply will last. One way to keep track of the amount of insulin in the container is to set aside the number of syringes needed for 940 units of insulin. Another might be to employ Braille, large print, tape recorders, or personal computers to record how much insulin has been used each day. Many diabetics who are blind like me realize the importance of keeping their blood glucose under tight control and follow regimes of insulin-mixing and multiple injections, both of which increase the need for precision. I have found the more precise the record of insulin drawn, the easier to predict safely when it is time for a new supply. Readers should note that though this method is not as precise, before drawing up insulin, users can gently shake the vial and, with practice, easily determine whether it is full, half full, or nearly empty.

The Possibility of Inserting a Needle into a Blood Vessel

Because injection sites are in fleshy areas and insulin needles are short, chances of inserting a needle into a blood vessel are minimal. The worst that can be done is to hit a small capillary, which would result in a small area becoming infused with blood--a *hematoma*. Again, it is unlikely the needle will be inserted into a small blood vessel. The amount of insulin entering the bloodstream via a capillary would be insignificant and cause no harm.

Something to Think About

I periodically have my insulin gauge checked for accuracy; it has always measured precisely. If a person is careful, difficulty in measuring insulin will not occur. I have found that inaccuracy is often the result of haste or carelessness. It is reported that insulin gauges are more accurate than sight. When the plunger is pushed firmly to the gauge, the same amount of insulin will be obtained every time. Sometimes my sighted friends make errors in drawing insulin. Perhaps they would be more accurate if they used insulin gauges! It is important to remember that syringes are mass-produced. Although there is quality control, some errors are made in syringe markings. If a gauge is used, the measurement will be accurate no matter what the syringe shows.

At first hearing, all this may sound like a lot to remember, but it is not difficult. Marla Bernbaum, M.D., CDE, Assistant Professor at St. Louis University Medical School, Department of Endocrinology, concludes, "In our experience here, most patients with diabetes who are blind or visually impaired have been capable of drawing their own insulin with complete accuracy."

Janet Lee, Director of the Independent Management for Blind Diabetics Program at BLIND, Inc., Minneapolis, MN, agrees: "In my 10 years of working with blind diabetics, hundreds of them, there have maybe been two who, because of a combination of disabilities, could not measure their own insulin."

And Ruth Ann Petzinger, RN, MS, CDE, Diabetes Care Manager/ Educator at St. Peter's Medical Center, New Brunswick, NJ, confirms: "During the time I have been working with persons with diabetes and visual impairment, I've never had a patient who truly wanted to be independent with insulin administration or blood glucose monitoring who was not able to achieve these goals."

Those testimonials are echoed by numerous specialists and diabetes educators. For example, Ann Reardon, RN, MSN, CDE, with the Georgia Department of Human Resources/Medical College of Georgia says, "In my experience, with proper training, almost all diabetics are able to prepare and administer their own insulin safely, regardless of visual impairment."

Ann Williams, MSN, RN, CDE, Diabetes Program Coordinator, Cleveland Sight Center, and her colleague Marylin Teasley, RN, CDE state: "In the last 8 years, we have taught about 800 people who are blind or visually impaired to measure and administer their own insulin independently. Vision loss does not preclude safe and effective insulin self-administration."

I have no problems managing and keeping my diabetes under control. I control it through the use of alternative techniques, some of which are described here. Many members of our organization, the National Federation of the Blind, use them daily to live active lives. With alternative techniques, blind diabetics can be as productive as when they were sighted.

People who need the benefit of firsthand experience should ask for assistance. Many are ready, willing, and able to help. Those of us with experience want your clients to know that no matter what their diabetes ramifications, they are not alone and do have options. We in the NFB know that blindness is not synonymous with inability.

Insulin Vials with Tactile Markings

Traditionally, insulins have been packed in identical vials (or pen cartridges), with the different types distinguished only by the writing on the label. Most who are managing diabetes, blind or sighted, mix insulins, but how do they tell their *R* from *NPH*, or *Lente*, or new quick-acting *Humalog*, if they cannot read the labels? For decades, blind diabetics, and those experiencing fluctuating vision (a condition in which vision may go from adequate to unusable, and perhaps back again, in days or hours), marked their insulin types with tape or rubber bands or asked someone else to read the labels. Rubber bands break, and tape falls off. Sighted aids are not always available, and people who are blind are entitled to their independence.

For 5 years, the Diabetes Action Network of the NFB campaigned to convince the Food and Drug Administration (FDA) and the insulin manufacturers to incorporate tactile markings on insulin vials. In letters, calls, and meetings with insulin industry and FDA representatives, the Diabetes Action Network pushed for permanent, easily detectable tactile markings on insulin vials, sufficiently prominent that individuals with neuropathy could detect them.

Our labors have borne fruit. The FDA has agreed change is overdue, and FDA officials gave us full credit for making the critical meetings happen. Shortly, all insulin vials will likely carry tactile distinguishing markings, a series of raised horizontal bars on the label. Probably one bar will mark the contents as "quick-acting," two as the familiar "Regular" insulin, and three bars as one of the suspension insulins. A four-bar marking will probably be reserved for any new insulin class not yet developed. If all proceeds apace, the new insulin vials should be on pharmacy shelves by the latter part of 1998. Once older insulin stocks are used or discarded, the consumer should encounter only tactile-marked vials. This should help make the process of truly independent diabetes self-management much safer for individuals who are blind.

I've Gotten Attached to My Insulin Pump

Veronica Elsea

Veronica Elsea is a professional musician with her own studio, and *a member of the Diabetes Action Network of NFB. Here she provides, based on her own experience, a detailed explanation of how blind diabetics who are blind can independently use insulin pumps.*

With the recent awareness of the benefits of tight glycemic control, many diabetics may be considering the use of an insulin pump. Yet along with the curiosity, excitement, and optimism come some challenges for blind persons. They must often start by convincing their health care professionals that yes, they can make use of this new technology--a tricky proposition if they have never actually seen or used the device. I hope that by describing how I manage my pump, this challenge will be more quickly and easily met.

I am totally blind, a type I diabetic, and I have been using the Disetronic (H-Tron V) insulin pump since September, 1991. The learning process was quick. I had the entire kit--pump, supplies, and manuals--sent to me ahead of time. I did not then own an optical scanner, so my husband read the manual to me, and I had the time to explore the pump privately. This process took one evening, and I found it very helpful.

The pump is small, about the same size and shape as a little travel pack of facial tissues. It has only three buttons, two on top and one on the front. There are no complex menus or screens to learn. In fact, for a person who is totally blind, the training is usually very quick because most "training time" is spent learning the print symbols for "cartridge," "battery," etc.

Everything the user does with the pump is confirmed by beeps.

Pressing once on either top button will bring three short beeps to indicate the pump is running; one long beep indicates the pump is stopped. When in stop mode, the pump also beeps every minute as a reminder. So if I'm removing my pump and don't wish to wake my husband while I shower, I temporarily turn off the beeps.

Batteries. The pump uses two batteries, which are very easy to install and remove. There is a low battery alarm which is described below.

Filling the cartridge. The pump uses a glass cartridge, holding 315 units of Regular insulin. Filling it is a very "blind-friendly" process. I simply place the cartridge in its holder and attach a needle to one end and its plunger to the other. After removing the cap from the needle, I insert the needle into an insulin vial, upright on my table. I then turn the whole works upside down and grasp the holder in my left hand. I can then push the plunger all the way up and begin pulling it out, slowly and steadily, filling the cartridge with insulin. The holder prevents the plunger from being pulled out too far.

The question most sighted people ask is about preventing air bubbles. I find it's easy to get air bubbles because it's hard to pull the plunger out evenly. So, after I fill the cartridge, I slowly push the plunger back in again--and surprise--the air bubbles are very audible! I usually do this a few times, pushing and withdrawing the plunger, sometimes tapping randomly on the holder. When I push in and hear nothing, I stop, pull it back out, and that's it! I then pull the insulin vial off, cap the needle, unscrew the plunger and the needle, put a little cap on the cartridge, and lift it out of the holder. Sometimes just to be safe, I fill the cartridge in the evening and let it stand overnight before placing it in my pump the next morning. This allows the air bubbles to dissipate. Disetronic is now recommending this procedure for sighted pumpers as well.

Priming the pump. Near the battery compartment there is a hole into which the cartridge fits. I insert what's called the "piston rod" into the cartridge, where the plunger had been. This piston rod is what moves, forcing the insulin out of the cartridge. Once the cartridge is in the pump, I pull off its cap and put on what's called the "gray adapter." It forms an airtight seal and has an opening in the top where the tubing is attached. By pushing a few buttons, I tell the pump it has a new cartridge, and it sets its display accordingly. The pump beeps when the process is complete.

Getting insulin where it's needed. The insulin is delivered through a needle or cannula, which is placed anywhere you'd give an injection with a syringe. I use only my abdomen; I find it easier and more reliable. I use a Teflon cannula called "Tenders," made by Disetronic. I find them easy to insert and very forgiving. In fact, if a person has any neuropathy in the hands, these cannulas and cartridges may prove quite a blessing since they're fatter and larger than regular syringes. The "Tenders" are inserted at an angle, up to 45 degrees or so. I just hold it at a slant, push it in, and don't worry about it. As one might expect, once I insert the cannula and remove its insertion needle, it is held in place with tape. With the new "Tenders", the tape is part of the cannula, so I no longer find myself holding something in place while searching for a piece of tape somewhere on a table! It's designed for one-handed operation by a sighted person, which means it can, without vision, certainly be done easily and comfortably with two.

Tubing. The cannula is connected to the pump through special tubing. One end of the tubing is pushed into the end of the cannula, and the other screws into the gray adapter, as mentioned above. Before I connect the tubing, it must be primed (filled with insulin). This is done very simply by pressing all three buttons at once. When priming, I hold the end of the tubing in my left hand, and extend one finger until it rests directly under the spot where the insulin will come out. When that finger is damp, I know my tubing is completely primed. I stop the insulin flow by pushing one button with my right hand. I then attach the tubing to the cannula. Priming is treated as a separate function because the pump keeps track of daily insulin usage, so the amount of insulin used in this process is not added on to the total.

Insulin delivery. With a pump, one receives insulin in two different ways, the basal and the bolus. When the pump is running, it will automatically deliver insulin every few minutes, having been programmed (set) for an hourly rate. For instance, my basal rate for the hour at which I write this is 0.4 units. The pump then portions that amount over the hour. I can set a different rate for each hour or make many of them the same, depending on my needs. (I keep a list of my rates in a file in my Braille Lite.)

The process of setting basal rates is one of counting beeps. With the pump stopped, I push one button to move from one hour to the next. The remaining two buttons allow me to go either up or down 0.1 unit at a time. There are special shortcuts (button combinations) for some tasks, such as setting all rates alike or repeating the same setting for the next hour, etc. And yes, if a person really gets lost, it is possible to just go back to "0" and start over.

When it is time to eat, or if one needs to take extra insulin because he or she is "high" (i.e., has elevated sugars), the pump can be told to give a "bolus." When the pump is running, a press of either button on top will deliver 0.5 units of insulin. So if a person wanted 3 units, they would press the button six times. The pump will beep as one presses the button and then will repeat the beeps back before actually delivering the insulin. By the way, these buttons are designed to be felt through clothing, so one need not stop and fish out the pump. I have often given myself a bolus while standing in the buffet line, making my food selection. In the same manner, one can temporarily reduce the basal rate in cases such as extra exercise.

Carbohydrate-counting. This is a skill learned as part of pump training. In my case, I take 1 unit of insulin for every 12 grams of carbohydrate, except in the morning, when 1 unit covers 10 grams. I worked with a dietitian to learn portion sizes and read food packages.

There are many print books which list the carbohydrate and calories for various foods, and I'm hoping we'll shortly find this information on line.

Alarms. The pump has alarms for low batteries, occlusion, electronic problem, "out of insulin," and end of use of your pump. Although the same beep sounds, the alarms behave differently. Disetronic has expressed willingness to make these alarms easier to understand by having the beep match the "error number." For instance, error 3 means a low motor battery. In the future, the alarm for this might be a repeating pattern of three beeps. But for now, we just have to learn what the beeps mean. An alarm will beep constantly until silenced. If nothing else is done, it will beep again in 1 hour. This process can go on for as long as 12 hours.

I have learned that I usually get about 2 months' use on one battery set. So if I'm planning a trip, I usually just change them when I think it's about time, not waiting for the alarm. Incidentally, the pump does not forget the basal settings when one changes batteries. The occlusion alarm, on the other hand, will emit the same constant beep until silenced. But it will sound again every time the pump tries to deliver insulin, every few minutes. It also puts the pump in stop mode.

The pump warns as one approaches the end of a cartridge. The user will hear one beep when there are 20 units of insulin left, (I often miss this one), two for 15, three for 10, four when there are 5 units left, and an alarm when it runs out. This alarm acts like the occlusion alarm, but it has of course been preceded by all those warnings.

The display. I have not found any way to read the display successfully; it's too small to read with my Optacon. This display shows the amount left in the cartridge, the total amount of insulin used since midnight, the amount and time of the last bolus, and the current basal rate. It also shows symbols or numbers as one primes, installs a cartridge, sets the clock, and sets basal rates. At first, I used a calculator to keep track of my insulin usage, but now I know that under normal conditions, a cartridge lasts me about 8 days. Once in a great while, I just ask my husband to check a number, or to double check my readjustment of my basal rates. I rarely miss this display. The clock is also set by counting beeps. It can get a bit tedious, though, since one can only go forward; patience is required when changing back to standard from daylight time.

Wearing the pump. The pump only weighs a few ounces, has very rounded edges, and is very rugged. Many people place the pump in a pants pocket or on a belt loop. I prefer wearing mine tucked in my bra or in a shirt pocket. If I'm wearing a very nice dress, I often put it around my waist. (One can buy all sorts of pouches for holding the pump.) It doesn't hurt to roll over on it, bump it, or anything. I find that I only occasionally startle someone who gives me a big hug and wonders what that "thing" is. With mine, I've gone swimming, hiking, shopping, dining, and more.

Until the arrival of the "Tenders," I carried the pump into the shower every day. I would put it in a bag that I could hang on the faucet or clip to a shower curtain, and yes, the tubing is long enough to allow plenty of room for moving around. Tubing comes in different lengths, although I prefer the shortest, 31 inches long.

Only once during an exuberant "good morning" did my guide dog reach up and catch her paw in the tubing. It's a weird feeling to catch the tubing on something, but it takes real effort to knock out the cannula.

Questions or problems. I have found the people at Disetronic to be very helpful when I had a problem. They've done very well at giving blind-friendly descriptions of things over the phone, listening to my suggestions, and sending me things for trial purposes.

Advantages. I really notice a difference in my control. I use less insulin, have fewer highs and lows, and just plain feel better. I also love the flexibility; I decide when it's mealtime and can easily make adjustments if I am surprised by things like a sauce they didn't mention, or a walk that was longer because some street didn't go through. I love the convenience of not having to carry around all those little bits and pieces. Here's one example: I regularly attend breakfast meetings. I test my blood before I leave home. Because I never know when breakfast will actually arrive, I wait until the meeting has started, then just reach up and push the button. People don't even notice that I'm doing it; their pagers and mobile phones are much louder. I feel very efficient and inconspicuous, just the way I like it. If I'm out and unable to test or don't get a valid test, I find the pump very helpful. I take the amount of insulin which will match the upcoming carbohydrate or familiar diet pattern, and know that it's easily straightened out later, just by pushing a button. I'm also not so worried about going out and getting in trouble from low blood sugars because there's no long-acting insulin. Once I eat something, I know I'll be okay. I sincerely hope that relating my experiences with the pump will promote constructive discussions with health care teams about whether or not the pump is right for blind diabetics, with considerations based on diabetes and not blindness.

Note on suppliers. Disetronic Medical Systems (H-Tron V Insulin Pump): 5201 River Road, Suite 312, Minneapolis, MN 55421-1014; telephone (800) 688-4578. Control buttons are raised and easy to distinguish by touch. The device has clear audio cues.

Minimed Technologies (Minimed 506 Insulin Pump): 12744 San Fernando Road, Sylmar, CA 91342; telephone (800) 933-3322. Control buttons require modification for non-sighted use. The device is not as accessible as the Disetronic, though some persons who are blind use it quite successfully.

New Insulin

NFB Diabetes Action Network

Eli Lilly & Co., maker of Humulin insulins, has marketed a new and radically different insulin product. Called *Humalog* (Insulin Lispro), it is neither R nor N nor L, but a new class, best described as "quick-acting."

Under development for some time, this new "insulin analog" was submitted to the FDA for evaluation in March, 1995. The FDA approval process is now complete. Humalog insulin's extremely rapid onset makes it unlike all others. It starts up in 10 to 15 minutes and peaks in 1 hour, whereas traditional "R" insulins start to act about 20-30 minutes after injection and peak in about 3.5 hours. For safety, it will initially be available by prescription only.

What is the role of this new insulin? Kelly Sego, Communications Associate at Lilly, describes Humalog as "another alternative," especially for those insulin users practicing "tight control" as spelled out in the Diabetes Control and Complications Trial. She says that for some users, Humalog, designed to mimic more closely the insulin produced by a healthy pancreas, may replace Regular insulin. With Humalog, insulin users can be more flexible in injection and meal scheduling. Ms. Sego reports that some of the test subjects were able to "inject while looking at their food."

Insulin is a powerful medication with serious consequences if used incorrectly. Humalog insulin starts to work almost immediately (much faster than Regular insulin) and demands a high degree of precision in dosage. Designed to peak quickly, it may help cut the frequency of insulin reactions, but its speed demands the user promptly follow injection with food. Anyone should, of course, remember to discuss any planned change in insulin regimes with a physician.

Avoiding Hot Insulin

Summer brings hours of fun at the beach, the park, the mall, or wherever, and blind diabetics may find themselves carrying extra insulin. That's a good idea, but they should remember that insulin is very sensitive to extremes of temperature. Don't most people remember the last time they got in a car after a day in the summer sun? It was an OVEN. A closed car in the summer sun can get up to 140° F--hot enough to kill a dog, and hot enough to cause chemical changes in insulin left in the glove compartment.

How hot is "too hot?" A good rule is that if it's too hot a place for a person, it's too hot to leave insulin there. If that insulin is allowed to get hot and then is used, it may turn out not to work, and this leaves sugars free to go up fast. Exposure to freezing or to high humidity can also damage insulin. One should be prepared to replace doubtful insulin--it's cheaper than an ambulance call.

Questions About Blood Sugar Control

Originally published under the title "Questions to Ask Your Doctor about Blood Sugar Control," this information comes from the National Diabetes Outreach Program, part of the National Institutes of Health.

The Diabetes Control and Complications Trial (DCCT) showed that insulin-dependent diabetics, who keep blood sugar levels as close to normal as possible, can reduce their risk of eye, kidney, and nerve diseases. A doctor can provide the best instruction on how to improve blood sugar control. Questions for the doctor may include:

1. What is my glycosylated hemoglobin (a test that measures average blood sugar over the past 2 to 3 months)? What is a normal glycosylated hemoglobin?

2. How can I get my glycosylated hemoglobin into the normal range?

3. How often, and under what conditions, should I test my blood sugar? What should I do with the results? What patterns should I try to achieve?

4. What changes should we make in my program as a result of the findings of the DCCT?

5. Do I have microalbuminuria (tiny amounts of albumin in urine, an indicator of early diabetic kidney disease)?

6. What effect has diabetes already had on my eyes and kidneys?

7. When should I get together with a dietitian to review what I eat?

8. What exercises are best for me? What adjustments to my food or insulin should I make if I plan to exercise?

9. What should my family and friends do if my blood sugar goes so low that I need their help?

10. What should I do about taking care of my diabetes if I plan to get pregnant?

11. How should I take care of my feet? [*Editor's Note: People with diabetes should take off shoes and socks for the doctor without being asked. Too many physicians neglect to check their feet.*]

12. Are there any diabetes groups I could attend in our area?

For an Information Kit, write: National Diabetes Outreach Program, One Diabetes Way, Bethesda, MD 20892-3600; telephone (800) 438-5383.

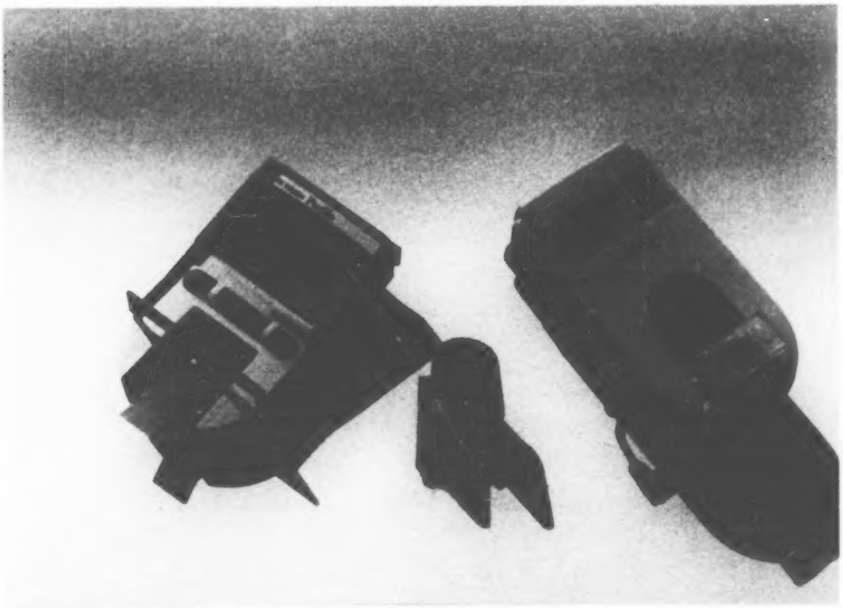
Talking Blood Glucose Monitoring Systems

Ed Bryant

I am often asked about the relative strengths and weaknesses of the various home glucose monitors equipped with voice enunciation available today. There is no "best" talking glucose meter; no one monitoring system is ideal for everyone. Therefore, the purpose of this review is not to endorse one. Features, prices, convenience, and clarity of instructions vary, and new equipment periodically appears. Although many companies make blood glucose monitors, and some of these display their results in large print, only three currently available meters allow voice enunciation, in which the device's voice synthesizer "speaks" the meter's instructions and test results.

The meter most often adapted to voice enunciation is the now-discontinued LifeScan One Touch II. Although LifeScan, Inc., of Milpitas, CA, the manufacturer, has ceased production, thousands remain on dealer shelves, and it is a proven and reliable piece of equipment. The "voice boxes," small synthesizer modules that plug into the glucose meter and give it voice, are not made by LifeScan, but by several competing firms described below.

LifeScan's new One Touch Profile is a refinement of their One Touch II, and the two meters have much in common. The Profile is slightly smaller, but its angled display screen is more than twice as large (though the extra space is used to convey more information, not larger numerals). (See illustration).



The LifeScan Profile (left) with Sure Drop Guide; LifeScan One Touch II (right) with Smart Dot; pictured separately, WACO-U-Finger Guide

Both meters use the same procedures, the same test strips, and the same detachable test strip holder. They are equally accurate, but the Profile, with its vastly expanded memory, allows the user to store up to 250 test records with date and time, to record insulin types and dosages with time and date, to insert "event markers" to help track the impact of specific activities on blood glucose levels, and to compute test averages for the past 14 or 30 days, along with many other features. To achieve these "bells and whistles," it is electronically more complex than its predecessor, so much so that voice synthesizers designed for the One Touch II will not operate with the Profile.

Although LifeScan once regularly supplied an instructional cassette with the One Touch II [still available upon request from LifeScan: (800) 227-8862], it makes no use of tactile landmarks and is of little utility to people who are blind. No cassette is offered with the Profile. There is real need for an adaptive instructional audiocassette designed for users who are blind of the LifeScan glucose meters.

Several manufacturers have been producing voice synthesizer units for the One Touch II and now offer updated versions of their voice boxes for use with the Profile.

Talking Glucose Monitors and Voice Boxes

The Voice-Touch speech synthesizers, for the LifeScan One Touch II or LifeScan Profile: The Myna Corporation (formerly TFI), 239 Western Ave., Essex, MA 01929; telephone: (508) 768-9000. Myna makes a pair of light, compact, convenient, and reliable glucose meter speech modules. The two models are not interchangeable. The Voice-Touch modules attach firmly to the meter, adding little bulk, and forming a single reliable unit. There are no separate switches to remember; the modules operate off the controls of the LifeScan monitor. The user may choose male or female voice enunciation. A Spanish-speaking Voice-Touch is now available; other languages are promised.

The Myna Corporation offers the Voice-Touch speech synthesizers for $189, the LifeScan meters alone for $135, or the combination for $324. An optional AC adapter is offered for $12. Myna's instructional cassettes clearly explain the speech modules, but do not describe operation of the LifeScan glucose monitors.

The LifeScan One Touch II meter and Voice-Touch speech synthesizer are also offered by NFB Materials Center, 1800 Johnson Street, Baltimore, MD 21230; telephone (410) 659-9314. The NFB offers the combination (meter plus voice module) for $309 (the lowest price for a talking glucose monitor in the U.S.), the voice module alone for $189, or the glucose meter alone for $120. An optional AC adapter costs $11. Addresses for the NFB and other suppliers may be found in the Appendix.

The Digi-Voice modules: Science Products, Box 888, Southeastern, PA 19399; telephone (800) 888-7400. Science Products makes several versions of their robust and reliable Digi-Voice speech module. The Digi-Voice Deluxe functions with the LifeScan One Touch II, as does one version of their smaller Mini Digi-Voice. Another version of the Mini Digi-Voice operates with the Profile.

Voice boxes designed for the One Touch II will not operate with the Profile, and vice versa! The Digi-Voice modules connect to the meter by a

22-inch patch cord, providing audio output for its readings. Controls are simple; on the Deluxe, a volume control knob and a toggle switch run the voice synthesizer, separate from the monitor's controls. The Mini's single button both turns on the voice box and adjusts the volume control, again separate from the meter's controls. Readings are announced in a clear, somewhat military, male voice. Clear and thorough cassette instructions explain both voice box and Profile meter (Science Products' instructional cassette does not cover operation of the One Touch II glucose monitor). Science Products sells the Digi-Voice Deluxe module alone for $275 ($395 with glucose meter), and the Mini Digi-Voice modules alone for $199 (9-volt battery included) or $219 (with AC adapter), or for $319 and $339 respectively, with glucose meter.

The Touch-N-Talk voice synthesizer units: Lighthouse Consumer Products, 36-02 Northern Boulevard, Long Island City, NY 11101-1614; telephone (800) 829-0500. The Touch-N-Talk II voice synthesizer operates with the LifeScan One Touch II meter, and the Touch-N-Talk P voice box works with the LifeScan Profile. Again, the two units are NOT interchangeable; voice boxes designed for the One Touch II will not work with the Profile! Meter and voice synthesizer join by a 12-inch patch cord. A brief instructional cassette is included. The unit uses one 9-volt alkaline battery, not included. An AC adapter is available at an additional cost of $11.95.

Perhaps in the interest of engineering simplicity, the Touch-N-Talk units have simple on-off switches and traditional volume controls. These voice boxes lack any provision for automatic shutoff, and forgetting to turn them off can lead to a run-down battery. The Lighthouse sells the Touch-N-Talk voice synthesizers for $219.95. They sell the LifeScan meters for $149.95 or the combination for $369.90.

The LHS7 Module, a new voice box for the LifeScan Profile: LS&S Group, P.O. Box 673, Northbrook, IL 60065; telephone (800) 468-4789. The small and light LHS7 attaches to the bottom of the Profile glucose meter by means of a Velcro patch and operates through the meter's controls. Two-position volume control (loud-soft); AC adapter included in purchase price. English-language voice only; no audiocassette instructions are provided. Cost: $199.

The Diascan Partner talking glucose monitor: Home Diagnostics, Inc., 2300 NW 55th Court, Suite 110, Ft. Lauderdale, FL 33309; telephone (800) 342-7226. The Diascan Partner is unique in that its voice synthesizer is internal, part of the meter itself. There is no separate speech module to attach or cords to plug in. This slim, "user friendly" unit allows somewhat more leeway in application of blood to test strip. With care, blood may be "painted" onto the strip; all other speech-assisted units require a hanging drop of blood. Powered by two AA batteries; weight approximately 8 ounces.

Some individuals with limited dexterity may find the Partner difficult to operate since its test strips are designed to receive the blood outside the machine, on a flat surface like a table, so there is no strip guide to aid correct finger placement. Others may appreciate this feature since it allows movement of strip to sample site, whereas other monitors require movement of sample site to meter.

An over-the-shoulder tote bag with adjustable straps is included. An easy-to-understand audiocassette with clear operating instructions is also supplied. Suggested retail price is $399.

Boehringer Mannheim Corporation, 9115 Hague Road, Indianapolis, IN 46250-0100; telephone (800) 428-5074, maker of the discontinued Accu-Chek Freedom System talking glucose monitor, is developing a new talking meter to be based on their Accu-Chek Advantage glucose monitor. Not a great deal is known as of this writing, but the company has a fine reputation for accuracy, and this new product is eagerly awaited.

Medicare

Medicare recognizes home blood glucose monitors as "Durable Medical Equipment," and coverage is provided for individuals using insulin under Medicare Part B. Glucose meters without audio output have one specification on the "Fee Schedule" (EO607), and glucose meters with voice synthesis or add-on voice boxes for home blood glucose monitors have another (EO609). It is essential to follow all guidelines for reimbursement.

Hints and Tips

If an insufficient amount of blood is placed on the test strip, most meters will indicate "not enough blood." It may even be necessary to prick a finger again. There are several possible explanations for this frustrating occurrence:

1. The initial drop of blood may be too small: Some do not bleed enough. They can get more blood by holding hands below waist level for about 15 seconds, shaking them, and/or washing/soaking hands in warm water for a few minutes before the test. Warm water stimulates the flow of blood to the fingers. A slightly longer lancet with deeper penetration may help some. "Milking the finger" (squeezing it gently) can also help, as can wrapping a doubled rubber band between the first and second joint of the finger to be lanced. This will help cause the finger to become engorged with blood. It is important to hold the rubber band down with the thumb while lancing and to remove the band as soon as lancing is complete.

2. There may be enough blood, but it can be placed onto the wrong part of the test strip: Some people bleed quickly and may lose the blood off the finger before they're ready. By the time they get finger to test strip, the blood has fallen in the wrong place. A fast bleeder needs to work closer to the test strip and perhaps to employ one of the blood placement aids discussed in this article. Users of the Diascan Partner should try bending up the tail of the test strip as an aid to location and placement.

3. Some enthusiastic people, placing the blood on the strip, press down too hard and push the blood out of its correct position, squishing it

onto the wrong part of the strip. It is best to deposit a hanging drop of blood very gently onto the test strip. Marla Bernbaum, M.D., writing in *The ADEVIP Monitor*, offers the following suggestion pertinent to diabetics with severe neuropathy, who wouldn't feel the otherwise painful "finger stick" she discusses here:

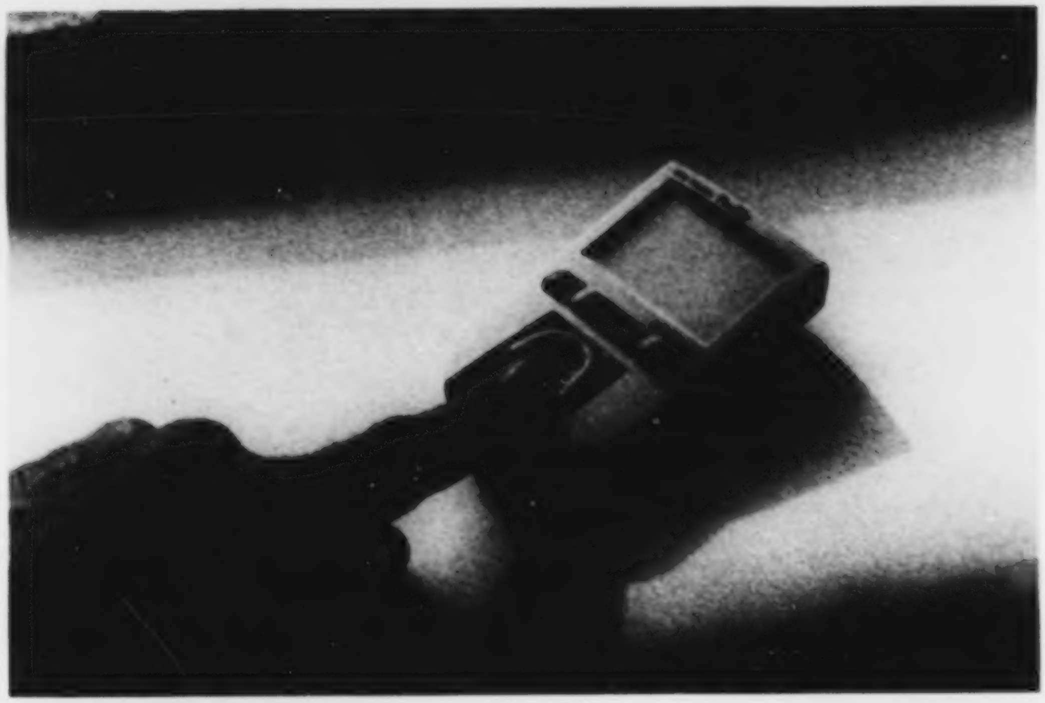
> "I have discovered another way to apply blood to the LifeScan test strip, which has been useful for several of our patients. This method allows them to stick the tip rather than the side of the finger. We use the same platform modification (described below), with a dot of Hi-Marks or t-shirt paint on each side of the strip guide near the depression where the blood is to be applied. For this approach, the meter should be turned sideways. The patient can then place the pad of the finger on the raised dot perpendicular to the length of the strip and rock the finger forward so that the tip of the finger lines up with the depression on the strip and deposits the blood droplet in the appropriate place. This method increases the portion of the fingertip that can be used and is preferable for some patients, particularly for those who bleed slowly and therefore must place the blood drop in precisely the right location."

LifeScan Modifications

In using any of the LifeScan One Touch series glucose meters, some blood placement problems can be solved by modification of the test strip holder (LifeScan Part #043-123; this same part fits all LifeScan One Touch meters). The idea is simply to provide tactile locating aids for finger location and placement of the blood sample on the test strip. A raised dot on either side of the test strip will work for some, but individuals with limited sensation in the fingertips may find a U-shaped guide more useful. Most individuals with diabetes puncture the side of a fingertip, but those with severe neuropathy, who can't feel the lancet, and who prick the center of the fingertip, may be helped by the U-shaped guide. With practice and the use of such tactile cues, individuals who are blind can correctly place blood samples on the test strip.

The test strip holder is detachable, and modifications as described will in no way interfere with the operation, accuracy, or cleaning of the LifeScan meter. LifeScan's Technical Services Dept. [phone (800) 227-8862] will provide a spare test strip holder upon request without charge. It is recommended that the modifications be to this spare.

The dots and U-shaped ridge can be created with t-shirt paint (see illustration) of the type that stands up sharply from a fabric surface.



The LifeScan One Touch Profile with a t-shirt paint finger guide.

Upon application, the paint spreads a little, so it should be applied sparingly. Best results come from "tack-painting," (i.e., applying a small amount and then letting it dry for a minimum of 12 hours), with subsequent applications to build up the height. It is best to practice first on some other material (posterboard or paper plate) since the paint can come out quickly. The test strip holder must be OFF THE METER when the t-shirt paint is applied. For best results, a test strip should be in the holder as an aid to placement of the dots or U-shaped ridge. T-shirt paint is inexpensive and is available at most craft and fabric stores. Although a full spectrum of colors is available, bright contrasting colors like orange may aid in low vision situations. Brands and types vary; one that produces a nice hard tactile ridge is preferable. Some paints feel too rubbery, and "puffy" paint flakes off too easily. It may be necessary to experiment.

Several vendors offer commercial alternatives to modifying the test strip holder. One slips over the LifeScan meter, and the other attaches directly to the test strip holder. Both aid proper finger placement and serve to guide the drop of blood more surely to the test strip. Science Products [address above, telephone (800) 88-7400] makes the Sure Drop, which slips over the body of the meter. The special Teflon-like coating on the surface of the device helps direct the blood, but it can be damaged by bleach or hard brushing and must be cleaned with mild soap and warm water. A Sure Drop made for the One Touch II will not fit the Profile, and vice versa. The unit for the Profile appears well-made and easy to use. Both units are priced at $24.95 each.

Smart Dot, 2655 West Central Avenue, Toledo, OH 43606; telephone (800) 984-1137: The Smart Dot clips directly to the test strip holder of ANY LifeScan One Touch meter. The same device fits Basic, One Touch II, and Profile. This plastic platform is easy to clean (both devices should be cleaned before the blood dries) and convenient to use, but there have been cases of its detaching from the meter in mid-test.

Don Kramolis and Gary Allman, Manual Skills Specialists at Blind Rehab Clinic, Veterans Administration Medical Center, Waco, TX 76700; telephone (817) 752-6581, ext. 7489, have developed the Waco-U-Finger Guide which, like the Smart Dot, fits any LifeScan Meter. Much like the t-shirt paint described earlier, the Waco Guide helps finger orientation. The Guide's other features help tactile strip insertion. Its designers do not sell finished guides, but offer plans and advice to interested individuals.

This evaluation of the strengths and weaknesses of the currently manufactured blood glucose monitoring systems with voice enunciation should prove helpful to persons with diabetes who are blind and those losing vision. They are just as capable as the sighted of independently testing their blood glucose levels and performing all the other tasks of daily diabetes self-management. Both persons who are blind and those who are sighted are encouraged to consult with their health care teams and with individuals experienced in use of glucose monitoring equipment.

Choosing the most appropriate home blood glucose monitor is an important step in diabetes self-management. As individuals who are blind increase their participation in the mainstream, efficient glycemic control is needed to maintain good quality of life. The Diabetes Action Network of NFB, a support and information network, welcomes input on blood glucose testing. [*Editors Note: One reviewer reports that some* *practitioners discourage sticking the tips of the fingers because of the pain involved for some people; therefore, one should consult the health care team to determine the best method.*]

Non-Invasive Glucose Monitors

NFB Diabetes Action Network

The weakest link in traditional blood glucose monitoring is the requirement to pierce a fingertip and draw a blood sample. More than 40 companies are researching new non-invasive blood glucose monitoring techniques that would dispense with the lancet. The new technology will give individuals an easy, painless way to check and control their blood sugar levels, helping them avoid or minimize long-term organ damage.

Several monitors currently under development use a beam of light reflected through the skin to measure blood glucose levels. This Near Infrared Spectroscopy (NIR), dubbed the "Dream Beam" by Futrex, Inc. of Gaithersburg, MD, one company researching the technology, can determine the chemical makeup of an object by analyzing the signal changes in the wavelengths of light after it has passed through that object. By measuring the glucose-reflected signals, concentration of blood sugar levels can be determined. However, glucose accounts for only 1/1000 of the mass of blood, making it hard to measure the wavelengths absorbed by glucose (also absorbed by other more sizable bodily components such as water and fat). The trick is to focus on those specific wavelengths that, although weakly absorbed by glucose, are even less captured by surrounding tissue.

Biocontrol Technology, Inc., based in Indiana, PA, was the first to submit an application to the FDA for approval. Their glucose meter, the Diasensor 1000, uses NIR technology to measure glucose levels. In 1996, an FDA advisory panel turned down the Diasensor, asking Biocontrol to improve its accuracy and provide better documentation before resubmission.

The Diasensor 1000 needs to be calibrated to the specific individual user. It cannot be used in a clinic or hospital setting and will need to be recalibrated periodically by Biocontrol. And it's big. The Diasensor 1000 is an 11" x 18.5" x 11" machine, not particularly portable. Its expected price will be between $6,000 and $8,000.

Another non-invasive technology, being developed by the University of California at San Francisco and Cygnus Therapeutic Corporation in Redwood City, CA, does not employ light. This monitor, the Glucowatch, measures sugar levels transdermally by means of a process called reverse iontophoresis. Worn like a wristwatch, this device uses a minute, steady electrical current to extract glucose molecules from the body, which are then continuously measured. It has two components: the electronics (the Glucowatch) and the sensitized patch (the Glucopad). Cygnus, the eventual manufacturer, envisions daily replacement of the sensitized patch to insure accuracy. Cygnus is currently in the process of miniaturization. When the production version of the Glucowatch is ready (which the company would like to offer for about $400), there will be more tests.

Solid-State Farms, from Reno, NV, is working on a portable non-invasive meter, the size of a pocket calculator, that will measure glucose levels with high-frequency electromagnetism. Their technology is based on the observation that different ionic solutes respond to alternating electromagnetic fields in predictable ways. These "normal" responses are impeded by the presence of molecules of substances such as glucose. The device uses the behavior of blood sodium as a referent, and since variations in blood glucose modulate the resonance of blood sodium in known amounts, measurement of that modulation should yield the percentage of blood glucose. The company, which claims a high degree of accuracy for its process, is continuing its research; clinical testing on humans has not yet begun.

The home blood glucose testing market is today worth well over $1.5 billion, and many companies are looking at possible entries. The field is constantly changing as new participants and technologies appear and some established players discontinue their efforts. No one knows who will be first!

When non-invasive monitors hit the market, they may cost several thousand dollars, though the price is expected to drop with time. The higher price of the non-invasive glucose meters will be at least partly mitigated by an end to the need for expensive test strips. Diabetics using a traditional meter, testing 4 times a day, can easily spend $1,000 per year on test strips alone.

The Center for Disease Control and Prevention estimates each year that 15,000 to 39,000 people become blind from diabetes. Just as there are a number of conventional glucose monitors for which voice synthesis is available, once a non-invasive monitor is approved by the FDA, company representatives say that voice synthesizers may become an accessory. Meter accuracy, accessibility, and affordability still need to be worked out. FDA approval will come when a manufacturer demonstrates its product is reliable and accurate. Demand for the new meters will be high. Companies involved in the research are aware of the immense profit to be gained by the first to come out with a non-invasive monitor. However, until affordability can be guaranteed, the non-invasive monitors won't benefit anyone--consumers or manufacturers.

Diabetes and the Feet

NFB Diabetes Action Network

Foot care is an ongoing issue for people with diabetes. Avoiding foot problems, dealing with minor issues before they become major, and preventing serious infections that could lead to amputation, are all concerns. For all the recent progress in wound care and intervention, prevention is still the best place to begin.

Over a period of time, diabetes can cause circulatory damage and neuropathy, both of which can affect condition of the feet. Because of impaired circulation, the body's ability to heal itself is diminished. Minor traumas, that might otherwise heal quickly, persist and can become infected. Diabetic neuropathy, nerve damage, can impair an individual's ability to detect foot problems. Because it doesn't hurt, the individual does not intervene, and small problems escalate into big ones.

The best place to start is with shoes and socks. Proper fit is essential. There should be no compromise, for there is too much to lose. One should make sure the shoe is wide enough and does not pinch the toes. Shoes that "breathe" (either leather or running shoes) are best. Sandals, especially those with a thong between the toes, should be avoided. Socks should be the seamless athletic type, made of cotton or one of the new fibers like *Thorlo*.

Before putting shoes on (and after they are taken off), diabetics should inspect their feet carefully, looking for anything out of the ordinary that might escalate from irritant into infection. This is a time to be thorough. Blisters, bunions, corns, splinters, raw or discolored patches, ingrown toenails, even "athlete's foot" fungus can require action. One should not assume any of these will go away by themselves. When in doubt, it is wise to consult a podiatrist.

Sight is not necessary to carry out daily foot inspections. Much can be revealed by feel and smell in looking for change, anything that shouldn't be there or that wasn't there before. Swelling, hot or cold patches, unexplained tenderness, or unusual odors all can indicate something is not right. It is amazing how much a tactile inspection (with fingertips, back of hand, or even forearm if neuropathy in hands necessitates) can reveal.

On any visit to the doctor, a foot inspection should be requested. Shoes and socks should be removed even before the doctor or patient asks. Also, the doctor may know that the progress of neuropathy can be measured by non-invasive tests of foot sensation. Such tests can be carried out with a device called a monofilament, which resembles a toothbrush with only one bristle. The doctor can obtain a monofilament by sending $15 and a request for a LEAP package to *Feet Can Last A Lifetime*, National Diabetes Outreach Program, 1 Diabetes Way, Bethesda, MD 20892-3600.

Keeping feet clean reduces risk of infection, should one break the skin. Washing with mild soap and medium-temperature water and drying carefully are recommended precautions. Many diabetics have abnormally dry feet, and treatment after bathing (or as needed) with a thin coat of moisturizing cream helps reduce risk of abrasion and infection. Moisturizer between the toes, however, should be avoided. The process of rubbing lotion into the foot provides a stimulating massage, good for the circulation, and offers one more chance to detect foot problems. Regular exercise helps stimulate circulation and keeps the feet healthy. A regular walking program will provide much benefit.

"Some foot problems can be prevented with good common sense, such as not walking barefoot on hot pavement," says Ron Scott, M.D., Director of the Wound Care Clinic of North Texas (at Presbyterian Hospital in Dallas), who also offers a reminder that cigarette smoking aggravates circulatory problems and that diabetics should not smoke.

Going barefoot is never a good idea for diabetics. Even at home, the carpet may hide staples and sewing needles, and any neuropathy may prevent feeling them. One should also check inside shoes before putting them on since small objects may fall inside them; thumbtacks, brads, or sharp nails may penetrate through the soles.

"Diabetics should NEVER use over-the-counter medications on their feet without the approval of their podiatrist or physician," says Neil Scheffler, M.D., a podiatrist from Baltimore, MD. "Corn or callus removers, for example, contain acids that can burn through the callus and normal skin as well with disastrous results."

"Home surgery" such as using a razorblade on corns or "planter's warts" is not recommended either. One should cut nails straight across and avoid shaving calluses. Minor irritations such as the above or even ingrown toenails are worth a call to the podiatrist. In many cases, Medicare covers such a service.

A podiatrist may recommend use of special therapeutic shoes or shoe inserts to help protect feet. As of May 1, 1993, if preconditions are met, Medicare will pay for certain types of footwear for diabetics.

The precautions described above should keep your feet out of trouble, but diabetes is unpredictable and problems can develop in spite of the best efforts. Quick intervention is called for any time trouble is suspected. Regular foot inspections can reveal an unfelt blister, undetected cut, or a puncture wound from a tack stepped on before the wound becomes septic.

Diabetes is the biggest cause of non-traumatic amputations in the United States. Most of these are lower limbs, where neuropathy, impaired circulation, and undetected, untreated injuries can combine to create non-healing, septic wounds. When gangrene (tissue death) develops, amputation can become necessary.

New medical developments have cut the rate of amputation. Curative Technologies Incorporated (CTI) operates the Wound Care Centers, a network of clinics where patients with severe septic wounds are given aggressive new therapies such as Procuren, a "growth factor" obtained from the patient's own body. CTI claims an 80% healing success rate, and notes, "These are patients who would likely have lost a limb to amputation."

Blind diabetics may never need such intervention if they stay vigilant, use common sense, and keep the health care team informed so that they keep their feet out of trouble.

Medicare Pays for Diabetic Footwear

NFB Diabetes Action Network

Since May 1, 1993, therapeutic shoes and inserts for diabetics have been covered under Medicare. Conditions, limitations, and exclusions, according to Health Care Financing Administration (HCFA) Program Memorandum B-93-1 (July, 1993, Publication 60 B), are discussed below.

To be eligible, an individual's physician must:

A. Document that the patient has diabetes;

B. Document that the patient has one or more of the following conditions:

1. previous amputation of all or part of the foot;
2. history of previous foot ulceration;
3. pre-ulcerative callus formation, or peripheral neuropathy with a history of callus formation;
4. foot deformity; or
5. poor circulation; and

C. Certify that the patient is being treated under a comprehensive plan of care for his or her diabetes and that he or she needs therapeutic shoes.

Therapeutic shoes purchased by or for patients with diabetes on or after May 1, 1993 are considered for coverage/reimbursement even if the physician prescribed or certified the shoes before May 1, 1993. For each qualifying individual, coverage/reimbursement is limited to one of the following within 1 calendar year:

(1) one pair of custom-molded shoes (including inserts provided with such shoes) and two additional pairs of inserts; or

(2) one pair of extra-depth shoes (not including inserts provided with such shoe) and three pairs of inserts; or

(3) an individual may substitute modification(s) of custom-molded or extra-depth shoes instead of obtaining one pair of inserts, other than the initial pair of inserts. The most common shoe modifications are: (a) rigid rocker bottoms, (b) roller bottoms, (c)

metatarsal bars, (d) wedges, and (e) offset heels.

Following certification by the physician managing the patient's systemic diabetic condition, a podiatrist or other qualified physician knowledgeable in the fitting of therapeutic shoes and inserts may prescribe the particular type of footwear necessary. The footwear must be fitted and furnished by a podiatrist or other qualified individual, such as a pedorthist, orthotist, or prosthetist. The certifying physician may not furnish the therapeutic shoe(s) unless he or she is the only qualified individual in the area.

The following HCFA codes apply to purchase and preparation of therapeutic shoes and inserts for individuals with severe diabetic foot disease:

Code	Definition
QO117	Fitting (including follow-up), custom preparation, and supply of off-the-shelf depth-inlay shoe manufactured to accommodate multi-density insert(s), per shoe.
QO118	Fitting (including follow-up), custom preparation, and supply of shoe molded from cast(s) of patient's foot (custom-molded shoe), per shoe.
QO119	Multiple density insert(s), per shoe.
QO120	Modification (including fitting) of off-the-shelf depth-inlay shoe or custom-molded shoe with roller or rigid rocker bottom, per shoe.

QO121	Modification (including fitting) of off-the-shelf depth-inlay shoe or custom-molded shoe with wedge(s), per shoe.
QO122	Modification (including fitting) of off-the-shelf depth-inlay or custom-molded shoe with metatarsal bar, per shoe.
QO123	Modification (including fitting) of off-the-shelf depth-inlay shoe or custom-molded shoe with off-set heel(s), per shoe.

HCFA stresses that the above codes are for diabetics only. To insure Medicare reimbursement, clients should follow HCFA guidelines.

For further information, one should contact the Medicare Durable Medical Equipment Office for a given state. The address and telephone number can be obtained from the Social Security Telecommunications Center at (800) 772-1213.

PART THREE: CURRENT MEDICAL ISSUES

Kidney Failure, Dialysis, and Transplantation

Ed Bryant

I have a special interest in kidney disease since I have had a kidney transplant over 13 years ago, and I feel great. I know people who've had transplants far longer than I have, and they're doing fine too. I hope the following answers some questions that arise whenever this sensitive subject is raised.

Many individuals with long-term diabetes face the prospect of kidney failure, end stage renal disease (ESRD). For them, there are three options for treatment. In hemodialysis, the patient's circulatory system is temporarily linked with a machine that performs the blood-cleansing functions of the human kidney. In peritoneal dialysis (CAPD or CCPD), a tube is inserted into the patient's peritoneal cavity, allowing urine and unneeded fluids to periodically drain from the body. The third option is kidney transplantation, in which a donated kidney is surgically implanted into the patient's body.

According to U.S. Renal Data System (USRDS) figures, there are more than 189,954 kidney patients undergoing dialysis in the United States today. U.S. Health Care Financing Administration statistics show that about 30% of kidney patients are there because of diabetes complications, and about 40% of those commencing dialysis or seeking a transplant at this time have diabetes. Some remain on dialysis long-term; others make use of the process while awaiting a kidney transplant. Before 1970, few ESRD patients with diabetes were dialysed; they simply sickened and died. Those who did dialyze faced a high mortality rate. Medicine has come a long way since then, and the odds have improved with the options. Dialysis techniques have improved substantially since my personal experience with them.

How is kidney failure measured? Several tests measure creatinine, a waste product from muscle mass. Although everyone produces creatinine, people whose kidneys are failing cannot properly excrete it. One test measures the amount of creatinine in the blood, and the other is "creatinine clearance," a 24-hour urine test. Normal blood creatinine for someone with healthy kidneys is 0.5 to 1.5. Government guidelines (April, 1995) recommend dialysis when the blood creatinine reaches 6 or above. However, some individuals with diabetes will experience kidney failure before that point. There is much variation between individuals. The actual range is from 3 to 8--but at or above 6, Medicare will pay for dialysis.

Creatinine clearance is considered a more reliable test. The numbers produced approximately indicate the percent of normal kidney function remaining to the individual. The 1995 government guidelines (Medicare Part B eligibility) state they will fund dialysis when the test produces a reading of 15 or less. This test measures how much creatinine comes out in a 24-hour period.

Individuals experiencing impaired kidney function, but whose test results indicate that they do not yet need dialysis or transplantation, might benefit from two new therapies. *Captopril* (trade name *Capoten*), a common blood pressure medication. In carefully monitored tests, it significantly reduced kidney degeneration. The FDA has recommended use of captopril for patients showing early signs of kidney damage. It cut in half the rate of kidney failure in its test population. (Note: Keeping blood pressure down in the normal range carries many benefits, such as reduced rate of kidney failure and less strain on eyes and cardiovascular system.)

Aminoguanidine is the second possibility. Tests are still underway, but this drug appears to reduce the damage done to the kidneys by excess glucose in the blood (and may reduce retinopathy as well).

Another option (currently under lab investigation) may be use of PKC-beta II inhibitors, chemical "blockers" that resist the complication-causing effects of high blood glucose. It will be years before we know if this approach has merit. Other options are certain to materialize, both for those with impaired kidney function and for those whose kidneys have failed.

Dialysis is not an "artificial kidney." A person undergoing hemodialysis must be hooked up to a machine 3 times a week, 3 to 4 hours per session. A normal vein cannot tolerate the 16-gauge needles that must be inserted into the arm during hemodialysis, so the doctor must surgically connect a vein in the wrist with an artery, forming a bulging *fistula* that will better accommodate the large needles needed for treatment.

Individuals with long-term diabetes often have cardiovascular and blood pressure problems. The added strain of dialysis, with its rise in blood pressure, straining eyes and heart function, can be too much for some. The dialysis patient with diabetes spends, on average, 30% more time in the hospital than does the non-diabetic dialysis patient, according to USRDS figures.

Some patients choose CAPD (continuous ambulatory peritoneal dialysis) or its variant, CCPD (continuous cycling peritoneal dialysis), both of which can be carried out at home, without an assistant. CAPD works inside the body, making use of the peritoneal membrane to retain a reservoir of dialysis solution, which is exchanged for fresh solution via catheter every 4 to 8 hours. CCPD makes use of an automated cycler, which performs the exchanges while the patient is asleep. Although more complicated and machine-dependent, it does allow daytime freedom from exchanges, and may be the appropriate choice for some. Though the risk of infections is heightened (as it is with any permanent catheterization), these two processes have advantages, one being that insulin can be added to the dialysis solution, freeing the patient from the need to inject, and giving good blood sugar control.

Kidney transplantation is a logical alternative for many. It substantially improves a patient's quality of life. Although the transplant recipient must be on anti-rejection/immunosuppressive therapy for life with the inherent risk from otherwise nuisance infections, a transplant frees the patient from the many hours spent on hemodialysis procedures each week, or from the periodic "exchanges" and open catheter of CAPD, allowing a nearly normal lifestyle. For those ESRD patients who can handle the stresses of transplant surgery, the resulting gains in physical well-being add up to real improvement in quality of life and overall longevity.

"Fifty percent of all kidney transplantations taking place today are into diabetics," states Giacomo Basadonna, M.D., Ph.D., a transplant surgeon at Yale University School of Medicine, in New Haven, CT. He reports that success rates are identical with kidney transplants performed on non-diabetic ESRD patients. "Today," he advises, "average kidney survival from a living donor is greater than 15 years."

One of the areas where we are seeing rapid improvement is immunosuppressive medication. Daniel M. Canafax, Pharm.D., F.C.C.P., Professor, College of Pharmacy, University of Minnesota, reports that Prograft (FK 506, tacrolimus) from Fujisawa, and Cellcept (RS 61443, mycophenolate mofetil) by Roche/Syntex, have been approved by the FDA; and Deoxyspergualin (DSG) by Bristol-Myers-Squibb, and Rapamycin (sacrolimus, Rapamune) by Wyeth/Ayerst, are currently being tested. The risk of rejection is always present, but each new development increases the chances of success.

Along with others knowledgeable in kidney transplantation, I would advise those contemplating a transplant to pick the best transplant center possible. After reading their statistics, one should ask staff of a prospective center the following questions. If they don't provide satisfactory answers, another center should be considered.

1. Do you have an information packet for prospective donors and recipients?

2. Can you put me in touch with someone who has had a transplant at your center?

3. What is your "graft survival" (success) rate?

4. Who will my transplant surgeon be? If a fellow or resident, will he/she be supervised by a practicing transplant surgeon?

5. How long have your current surgeons been doing kidney transplants? How many have they done? (Even though a given center has 35 years' experience with kidney transplants, it is of no consequence if the likely surgeon has only done 15 in his or her career.)

6. What is the average post-operative stay in your hospital?

7. When I come for my transplant, or come back for follow-ups, will there be any affordable housing for me and/or my family (i.e., Ronald McDonald House, or other lodging with discount rates), or will I get stuck in a luxury hotel for $90 a night?

8. How often will I need to come back to the center for follow-ups? Can my nephrologist do the blood tests and send you the results?

9. Can you recommend a nephrologist in my area? Do you correspond with this physician?

10. Do you have a toll-free number to call for after-transplant information?

11.What is your policy on people with insufficient health insurance? Will you work with an uninsured patient? What will it cost?

12. Are you prepared to satisfy my doubts? Will you show me the documents that answer my questions? Will you guarantee the price quoted?

To a prospective recipient, this may all sound daunting, but the worth of the procedure to someone who needs it may best be illustrated by these comments from some people about their own transplants:

* Eivind Frost, from Montana, received a cadaver kidney in 1973 at University of Minnesota Hospital in Minneapolis and is doing fine. He tells us, "I've been feeling great for 23 years now."

* Ken Carstens, from Minnesota, who received his kidney transplant at University of Minnesota Hospital in Minneapolis on September 10, 1975 states, "It's been 21 years now, and I'd make the same choice again."

* Karen Mayry, from South Dakota, received her kidney transplant at University of Minnesota Hospital in Minneapolis on January 12, 1977. She declares, "I feel great!"

* Betty Walker, from Missouri, received her transplant on July 13, 1978 at Yale--New Haven Hospital in Connecticut. In her words, "I was just existing on dialysis; my transplant gave life back to me."

* Eric Knoeppel, from Missouri, received his kidney at Clarkson Memorial Hospital, in Omaha, NE on July 5, 1981. He says, "After my transplant, it was nice to be able to go back to work! Before, I was

dependent on government assistance."

* Linda Bingham, from Ohio, who received a dual transplant (kidney and pancreas) at University of Cincinnati Hospital on December 10, 1981 says, "I feel great. I have been given a whole new life."

These individuals know what they're talking about. Collectively, they have more than 113 years' experience living with kidney transplants, and all of them would choose a transplant again. Although kidney transplantation is not for everyone, it should be given strong consideration.

What percentage of persons with type I diabetes will face ESRD? Current statistics suggest 20%.

What is the success rate for kidney transplant surgery? According to the *United States Renal Data System 1993 Annual Data Report*, published by the National Institutes of Health, it is about 75% for a cadaver-donated kidney, better than 90% with a kidney donated by a living relative, with an overall success rate of better than 85% (better than 90% in some centers).

Must the ESRD patient be on dialysis before being considered for a transplant? No, although some behind-the-times nephrologists still believe so. University of Minnesota Transplant Center, which pioneered diabetic kidney transplantation, recommends that once the physician has determined kidney failure is on the way, further delay could be harmful. The more time spent subjecting the patient's body to the toxic excesses of kidney failure and the strains of dialysis, the greater the risk of serious complications like retinopathy and cardiovascular (heart) degeneration. The success rate for individuals with diabetes needing kidney transplantation is approximately the same as for non-diabetic transplant recipients. Diabetics, furthermore, tend to take better care of themselves than does the general public.

A nephrologist (kidney specialist) should be able to tell a person approaching this subject more about his or her options. For information about kidney transplantation, one should contact a reputable transplant center (there are more than 239 in the U.S. today) or the United Network for Organ Sharing, 1100 Boulders Park, Suite 500, Richmond, VA 23225; telephone (800) 243-6667. For information or assistance with interpreting transplant center data, one may contact the Health Resources and Services Administration, Bureau of Health Resources Development, Division of Organ Transplantation, 5600 Fishers Lane, Room 11A22, Rockville, MD 20857; telephone (301) 443-7577.

Renal failure is not a kiss of death. There are options, and at least one of them will be right for most people facing this condition. Diabetics should work to keep their condition under good control to cut the risks, but if renal failure happens (as it did to me), remember that with proper care, one stands every chance of living just as long as would have been possible with healthy kidneys. I've had my transplant 13 years, and I'm planning to be here a long time more.

Pancreas Transplantation: Should Blind Diabetics Be Excluded?

Francisco S. Escobar, III, M.D.

Dr. Escobar, Senior Staff Surgeon, Division of Transplantation Surgery at Henry Ford Hospital, delivered this keynote address at the annual meeting of the Diabetes Action Network of the National Federation of the Blind, in Detroit, MI on July 3, 1994.

Standing at this podium today is certainly a privilege for me because one of my mentors, Dr. John Najarian, spoke to you a few years ago about pancreas transplantation. Before 1980, transplant surgeons were reluctant to perform kidney transplants in diabetics because of the consensus opinion at that time that patient and graft survival was particularly poor in diabetics. Through the efforts of Dr. Najarian and others, kidney transplantation is now the preferred treatment for all patients with end-stage renal disease (ESRD). In 1994, diabetic recipients of kidney transplants have excellent patient and graft survival rates, similar to non-diabetic patients.

At Henry Ford Hospital in Detroit, Dr. Mozes and I, along with many other health care professionals, are continuing in this tradition. Since January, 1968, more than 1,000 kidney, 150 heart, 40 liver, and 30 pancreas transplants have been performed. For kidney transplants performed prior to 1992, we have 1-year actuarial patient survival, and kidney function rates of 93% and 82%, respectively. Although our series of pancreas transplants since 1992 is relatively small, we have 1-year actuarial patient survival and pancreas function rates of 85% and 80%, respectively. Our priority in the Henry Ford Health System is to provide cost-effective health care of the highest quality, strengthened by excellence in education and research.

Almost a year ago, I saw a patient to discuss pancreas transplantation. At that time, Sharon was an attractive, vibrant 27-year-old female who had diabetes for 24 years. By 1988, she was legally blind and had renal failure. In 1989, she had a cadaveric kidney transplant which was eventually lost to chronic rejection. In 1991, she had a second kidney transplant, receiving the organ from her father. In 1993, she was physically active and lived independently. She was also taking a course in medical transcription at the local community college. She strongly desired to be insulin-independent and was interested in pancreas transplantation. Although she had no absolute medical contraindications for pancreas transplantation, her insurance company denied her request for coverage because she was blind.

As I was preparing for this meeting, I read an article in your paper, *Voice of the Diabetic*, by Dr. Homer Page, who states:

> I believe. . . that persons who are blind are capable of living normal fulfilling lives. In many ways, society, through its ignorance and occasionally through its hostility, tries to prevent us from living the lives that we know are possible for us. We know that if we work together to create opportunities and to support one another, our chances to fulfill our lives

> will be greatly increased. . . Whether we are fighting discrimination, working with legislators, or taking on the media, we know that our work is of high quality.

I was encouraged by this creed. Perhaps you, the Diabetes Action Network, would consider the question of whether patients who are blind should be excluded from pancreas transplantation. Would you take up the charge, with the assistance of health care professionals, to help patients like Sharon?

Before you answer, I would like to review five pertinent issues:

1. Kidney transplantation not only improves the quality of life for ESRD patients but is also cost-effective relative to dialysis for the government and insurance carriers.

2. Like heart or liver transplantation, kidney transplantation is a life-saving procedure for diabetic patients on dialysis.

3. Like other medical therapies (e.g., total hip replacements), pancreas transplantation significantly improves the quality of life for patients.

4. Since pancreas transplantation is a complex procedure with significant morbidity, is this "surgical" treatment of diabetes worse than the secondary complications of the disease?

5. And finally, does pancreas transplantation halt, reduce, or prevent the secondary complications of diabetes?

As stated in the *U.S. Renal Data System 1991 Annuai Report*, ESRD is a devastating medical, social, and economic problem for patients and their families. As many of you know, the initial diagnosis of the disease and the recognition of the need for continual therapy are likely to make the patient feel vulnerable, dependent, and near death. After dialysis is initiated, other problems become more prominent. Social adjustments to substantially elevated mortality risks, dependency, reduced quality of life, low likelihood of returning to work, and dramatic costs are all part of the problem.

Although dialysis has dramatically improved the life expectancy of patients, ESRD is still a serious problem. According to the U.S. Renal Data System, overall mortality in dialysis patients is high relative to the general population. For dialysis patients, at age 40 years, life expectancy is estimated to be 8.8 years, whereas in the total U.S. population, at age 40, life expectancy is over 37 years. For dialysis patients at age 59 years, life expectancy is estimated to be 4.2 years, whereas in the total U.S. population, life expectancy is over 20 years. The mortality rates for colon cancer patients are similar to those for dialysis patients, whereas prostate cancer patients have a somewhat better survival rate than do dialysis patients.

Many investigators have therefore focused on careful quantitative comparisons of life on dialysis or with transplantation. One study by Dr. Roberta Simmons, conducted at the University of Minnesota in the early 1980s, showed that the quality of life of renal transplant recipients surpassed that of Continuous Ambulatory Peritoneal Dialysis (CAPD) or hemodialysis patients. Among males, only 19% of hemodialysis patients and 35% of CAPD patients were at work or school full-time compared with 64% of transplant patients. In addition, transplant patients had significantly higher scores regarding their physical, emotional, and social well-being. As Dr. Simmons stated, "Quality of life remains an ethical issue in transplantation because of the high cost of this technology and the inevitable decisions which will need to be made concerning resource allocation."

In a recent *Newsweek* poll, 74% agreed that health care reform will lead to rationing, in which some forms of medical care will not be covered by basic insurance because they are too costly, too much of a long shot, or not essential. Organ transplantation is often criticized as too costly, given other health care needs, such as pre-natal care and childhood immunizations. Dr. Roger Evans of the Mayo Clinic has recently reviewed this issue in an article entitled, "Organ Transplantation and the Inevitable Debate as to What Constitutes a Basic Health Care Benefit." In 1992, an estimated $3.2 billion or 0.4% of total U.S. health care expenditures was spent on organ transplant recipients. However, transplant expenditures are rather modest when compared with treating AIDS patients, (i.e., over $10 billion). While the 5-year patient survival for AIDS is 0%, the estimated annual expenditure per patient at 5 years is $38,300. As Dr. Evans states, "Devoid of health care benefits, dead people are inexpensive to maintain." The 5-year patient survival for dialysis and kidney transplantation is 34% and 77%, respectively and the annual per patient costs of dialysis and transplantation (without the initial procedure costs) are $33,165 and $6,900. If one includes the initial procedure costs of transplantation (which are estimated to be $82,908 for the first year), the aggregate costs of renal transplantation become less than dialysis during the third post-transplant year. Relative to AIDS, dialysis, and cancer, the costs and benefits of kidney transplantation are more favorable.

Now that I have established that kidney transplantation improves the quality of life for ESRD patients and is cost-effective relative to dialysis, I would like to address my second point. Like heart or liver transplantation, kidney transplantation is a life-saving procedure for diabetic patients on dialysis.

Generally, most health care professionals, even within the transplant community, place heart and liver transplantation on a higher plane than kidney or pancreas transplantation because the former are "life-saving" whereas the latter are "life-improving" organs. Patients waiting for heart and liver transplants, unfortunately, do not have alternative "life-sustaining," non-surgical therapies, such as dialysis for renal failure and exogenous insulin for diabetes mellitus. As you would expect, the United Network for Organ Sharing reported in 1993 that 12.2% of patients died waiting for a heart transplant, 7.9% died waiting for a liver, 3.8% died waiting for a kidney, and 1% died waiting for a pancreas. Patients who are accepted to wait for kidney and pancreas transplants are highly selected; patients with serious comorbid conditions and high surgical risks are not accepted on the transplant waiting lists.

Dr. Friedrich Port and others recently studied the survival probabilities for dialysis patients versus cadaveric renal transplant recipients in Michigan. The long-term risk of dying was slightly reduced (by approximately 10%) when patients with glomerulonephritis were transplanted. On the other hand, the long-term risk was greatly reduced (by approximately 85%) when patients with diabetes received a kidney transplant. For diabetic patients on dialysis, kidney transplantation can be a life-saving procedure.

Although we all agree that patients with diabetes like Sharon should receive a kidney transplant, whether she should receive a pancreas transplant is debated by most insurance carriers. As Anne Nettles from the University of Minnesota has written:

> In one very unusual situation, a patient's husband was forced to resign from his job to care for his wife, who suffered bouts of unconsciousness from hypoglycemia and lethargy from hyperglycemia. [A] major reason for pancreas transplantation is the patient's often irrepressible desire for a cure. This desire [was]...reflected in this...quote [from a patient]: (A few months without diabetes was worth the surgery, the cost, the rejection, and [even] the loss of the pancreas transplant).

Clinical experiences from many centers now suggest that pancreas transplantation can substantially improve the quality of life for people with diabetes. Zehrer and Gross have reported that with a functioning graft, 68% of the patients expressed overall satisfaction with their lives, 78% could care for themselves, and 89% felt healthier since their transplants. Patients specifically cited the benefits of pancreas transplantation as freedom from insulin injections, freedom from insulin reactions, freedom from a specialized diet, and more hope for the future.

If this is true of sighted patients, would pancreas transplantation be even more beneficial for diabetics who are blind? As this audience knows well, because of visual and physical impairments, self-care activities are particularly difficult for blind diabetics unless techniques and equipment can be individually modified. Even then, adequate glucose control is difficult. Furthermore, the visually impaired have significant levels of depression, poor self-esteem, and decreased psychological well-being. *[Editor's Note: This statement may be misunderstood and misapplied outside the clinical context of the remark. The National Federation of the Blind, for example, has thousands of members, and most have no problem with self-care activities. With proper training and opportunity, blind people can do what they want and be involved in the mainstream. The old myths about blind persons being depressed and having more psychological problems than their sighted peers still exist even though blindness is demonstrably not synonymous with hopelessness or inability.*] Although there are no specific studies regarding these issues for blind recipients of pancreas transplants, blind diabetics would probably benefit from a pancreas transplant more than would sighted persons with the disorder.

If this is the case, then why would an insurance carrier deny Sharon's request for a pancreas transplant? In this era, health care reform, managed care, and managed competition have forced health care professionals to adopt more conservative and cost-efficient practices. Unlike renal transplantation, we do not have sufficient data to compare the costs of pancreas transplantation and the consequent savings from normoglycemia with the costs of routine diabetic care and the subsequent complications of hyperglycemia. However, the debate about pancreas transplantation has focused mainly on the control of diabetic complications rather than on quality of life. There are many other medical therapies and procedures, such as total hip replacements, which are done mainly for quality of life.

Total hip replacement (THR) is a good example of an expensive, highly technical elective procedure with increasing utilization. As reported by Friedman and Elixhauser, THR is one of the most costly procedures, contributing between $1 billion and $2 billion of Medicare expenses in 1987. Unlike pancreas transplantation, hip replacements are routinely covered, almost without question, by insurance carriers. Hip replacements have been typically performed on patients greater than 55 years old to reduce pain and functional limitation associated with arthritis. Wilkund and others have shown that after hip replacements, patients had significant improvement regarding pain, energy, sleep, and social isolation. Like pancreas transplantation, hip replacement clearly improves a patient's quality of life.

Other studies, however, have found only a small improvement in mobility or economic benefits because two thirds of the patients are more than 65 years old and are not employed. Sheppard and others reported that patients more than 80 years old had a hospital mortality of 4%, a hospital morbidity of 77%, and a 5-year patient survival rate of 50%. Do total hip replacements constitute heroic care for the elderly? Because most of these patients were able to maintain independent living, many believe that hip replacement is cost-effective compared to maintaining a non-independent patient in a nursing home. Isn't pancreas transplantation similar to hip replacement? If so, why don't all insurance carriers cover pancreas transplants for blind people?

In general, the debate focuses on the risks of pancreas transplantation procedure and immunosuppression versus the control of retinopathy and neuropathy. Since pancreas transplantation is a complex procedure with significant morbidity, is this "surgical" treatment worse than the secondary complications of the disease?

With advances in organ transplantation and fewer restrictions on patient selection, an ever-increasing number of patients are becoming candidates for transplantation. From December, 1966 to January, 1994, 5,540 pancreas transplants were reported to the International Pancreas Transplant Registry. Of these, a total of 3,662 pancreas transplants were performed in 88 U.S. centers. In 1993, 765 patients (or 21% of the entire 28-year experience) received pancreas transplants. As of April, 1994, 1,156 patients were waiting for a pancreas transplant. As reported by the

United Network for Organ Sharing, the overall recipient actuarial survival rates at 1 and 3 years are now 91% and 84%, respectively. Overall pancreas graft function rates at 1 and 3 years are 72% and 62%, respectively. Simultaneous pancreas-kidney transplants from cadaveric donors have the best pancreas function rates of 76% at 1 year and 68% at 3 years. For these transplants, the 1-year pancreas function rate continues to improve each year, being 70% in 1987 and 81% in 1992. A successful pancreas transplant is the only therapy currently available that will produce a sustained, normoglycemic, insulin-independent state.

As with any surgery, pancreas transplantation does have risks. Normoglycemia has its price. Alan Cheung and others at the University of Minnesota have shown that acute morbidity of simultaneous pancreas-kidney transplantation is higher than cadaveric kidney transplantation for individuals with type I diabetes. Complications, more common in pancreas recipients, were wound problems, urologic problems, rejection episodes, and infections. Patient survival and kidney function are, however, not affected by the addition of a pancreas in patients less than 45 years old.

Most diabetics do not want pancreas transplants primarily to slow the course of renal failure. They place more importance on metabolic control. They want freedom from personal, social, and dietary restrictions. As one patient said during a discussion of risk factors, "My doctor says my risk of dying is 50% from cardiac disease... So what difference is it to me if my pancreas transplant is risky?"

For years, diabetes experts have emphasized normal blood sugars thinking that this will prevent, postpone, or even reverse the long-term complications of diabetes. As the authors of the Diabetes Control and Complications Trial (DCCT) have stated, "Although the daily management of (diabetes) is burdensome and the specter of metabolic decompensation ever-present, long-term complications... have caused the most morbidity and mortality since the introduction of insulin therapy." As you know, individuals with diabetes are 35 times more likely to be blind, 17 times more likely to have renal failure, 5 times more likely to have an amputation than the general population, and twice as likely to develop heart disease. This diabetes trial compared conventional therapy, consisting of one or two daily insulin injections guided by daily self-monitored blood sugars, with an intensive therapy regimen, consisting of three or more daily insulin injections guided by 4-times-a-day blood sugar measurements. Although intensive therapy was able to lower mean blood sugar from 231 to 155 mg/dl, the glycosylated hemoglobin, a measure of blood sugar control, still remained elevated 40% above the normal limit. Of all currently available treatments for diabetes, only pancreas transplantation will restore normal blood sugars and normal glycosylated hemoglobin. Furthermore, the intensive regimen resulted in a 3-times greater risk of severe hypoglycemia. Did the intensive regimen, the "best" known medical therapy, affect the secondary complications of diabetes? The intensive therapy slowed, but did not halt, the progression of retinopathy and nephropathy.

I now come to the last issue I would like to discuss. How does pancreas transplantation compare with an intensive insulin regimen? Does pancreas transplantation halt, reduce, or prevent the secondary complications of diabetes? First, several studies are consistent with the hypothesis that the recurrence of diabetic nephropathy is prevented by a successful pancreas transplant. Second, Secchi and others from Milan studied the effects of kidney transplantation alone and pancreas-kidney transplantation on diabetic neuropathy. Peripheral nerve function was improved in both groups during the first year, which may reflect nerve recovery from uremia. At 2 years, however, only the pancreas group continued to improve. From this and other studies, normoglycemia appears to have a beneficial effect on neuropathy. Third, correction of uremia by kidney transplant alone, however, has been reported to slow the progression of early diabetic retinopathy in some recipients. In a study from Munich, visual acuity after simultaneous pancreas-kidney transplantation improved by at least one line (on an eye chart) in 56% of patients, remained stable in 32%, and deteriorated in 12%. Advanced retinopathy is probably not altered by pancreas transplantation.

As one of my mentors, Dr. Sutherland, has written, "Ideally, pancreas transplantation should be applied early in order to influence favorably the course of secondary complications." Pancreas transplantation should be performed in patients with secondary complications of diabetes who have reached or are progressing to, a stage more serious than risks of surgery or the side effects of immunosuppression. Patients will benefit. They will report an improved quality of life with greater personal, social, and dietary freedom than while they were on exogenous insulin. With this in mind, should individuals with diabetes who are blind be excluded from pancreas transplantation? As Jane Bryant of *Newsweek* has stated:

> When it comes to their health, Americans with insurance won't accept limitations lying down. . . . When doctors decline to operate or insurers refuse to pay, patients are going to court for a second opinion. . . . The most visible issue is the bone marrow transplant for women with advanced breast cancer (estimated costs of $60,000-150,000).

According to Robert Griss, Director of the Center on Disability and Health in Washington, DC, "Any decision not to treat is [however] illegal [now] under the 1990 Americans with Disabilities Act if treatment is withheld because of patient's presumed low quality of life." And that includes blind diabetics.

So follow your creed which Dr. Page eloquently stated in the *Voice of the Diabetic*. Fight discrimination, work with legislators, and take on the media to help blind patients like Sharon improve their quality of life with a pancreas transplant.

Arthritis and Diabetes: A Common Association

Thomas Pressly, M.D.

Dr. Pressly is a practicing rheumatologist at Willis/Knighton Hospital, and a consultant in rheumatology at Shriners Hospital for Crippled Children in Shreveport, LA. Diabetes is no stranger in the Pressly household. His wife, Tracy, has been insulin-dependent for 28 years.

Arthritis and diabetes are both common conditions that affect many Americans. The musculoskeletal system can be affected in diabetes, leading to conditions such as arthritis. For several reasons, diabetics should be aware of this association. In the presence of musculoskeletal complications, the knowledgeable diabetic can decrease pain, improve function, and attempt to decrease the progressive severity of some forms of arthritis. Moreover, the individual with diabetes should know that medications used for the treatment of arthritis can interfere with the treatment of diabetes. Modifications in medications sometimes must be made.

Arthritis is defined as inflammation of the joints. There are over 100 different types of arthritis. Almost 40 million Americans have these disorders. Fourteen million Americans have diabetes mellitus. These common disorders can occur together. As stated previously, medications used in the treatment of one disorder can lead to the development of the other and/or can interfere with its treatment.

The most common types of arthritis are osteoarthritis, rheumatoid arthritis, crystalline induced arthropathies (e.g., gout), and systemic lupus erythematosus (SLE). Osteoarthritis is also known as "degenerative joint disease" or the "wear-and-tear form" of arthritis. Occurring commonly in families, it has recently been proven to be an inherited disorder. It commonly affects the hands, spine, hips, and knees. This form of arthritis is usually limited, affecting only the joints, and is more painful later in the day. It is thought to be caused by a defect in cartilage that results in bone destruction.

Rheumatoid arthritis, in comparison, can affect most of the joints of the body and is associated with prominent morning stiffness and swelling. It can involve internal organs such as the heart and lungs. Early diagnosis is important so that medications called remittive agents, which can slow down the progression of the disorder, can be administered prior to bone destruction.

Crystalline induced arthropathies are disorders such as gout and pseudogout. The joint most often involved in gout is the first metatarsal joint located at the base of the big toe. Many times, people wake up with excruciating pain in this joint and then note total resolution of pain within 3 to 4 days. Bone destruction can occur with gout, but there are medications that can stop the process. Ninety percent of people with gout have one episode. The two most common factors that cause gout to flare are use of aspirin and alcohol. Gout also can be flared with the use of Thiazide diuretics (e.g., HCTZ, Dyazide, Maxide), which are commonly prescribed for high blood pressure. Pseudogout is a form of arthritis caused by the deposition of calcium pyrophosphate crystals. An increased incidence occurs in people who have metabolic disorders such as diabetes mellitus. It commonly affects the knees and wrists. Like gout, it usually appears as a flare of severe pain, swelling, and redness in a joint. The condition spontaneously improves in a few days.

Systemic lupus erythematosus (SLE) is a form of arthritis that can have marked internal organ involvement. Although any age group can be affected, it commonly occurs in women in their 20s. Early diagnosis and close follow-up are essential to treat organ involvement. Lupus is a disorder that can vary in severity. There are 10 different sub-types of lupus which can vary from a syndrome of rashes and joint pains to life-threatening brain and kidney involvement. Certain medications--mainly heart medications such as Procanimide and Quinidine--can cause SLE. When the medications are stopped, SLE disappears.

Because osteoarthritis, rheumatoid arthritis, gout, and lupus are so common, many people with these disorders will also have diabetes mellitus. Diabetes also has specific musculoskeletal manifestations. Three categories of musculoskeletal disorders are caused by diabetes mellitus. Neuropathies (nerve involvement); arthropathies (disorders of the joints and connective tissues); and problems with skin, tendons, and muscles.

Neuropathies. Several forms of neuropathies (nerve problems) can occur in diabetes. Distal sensory and sensory motor disorders involve nerves supplying feeling and muscular control over the hands and feet. Patients note a loss of sensation in a stocking/glove distribution. On examination, decreased vibration and position sense and decreased tendon reflexes are found. Neuropathies, inflammations of certain nerves of the body, can result in muscle weakness. The most commonly affected nerves are the cranial nerves to the face. This induces eye muscle weakness and weakness of the muscles of the face. Diabetic amyotrophy damages the nerves to the hip and leg muscles, leading to weakness of the extremities. Infrequently, it will involve the arms. This disorder frequently occurs in those with only mild diabetes and can spontaneously resolve. Radiculopathy is distress to major nerves coming out the back. This may be due to death of the nerve (infarction) and will result in electrical shooting sensations down the legs. This is frequently confused with symptoms of a herniated disc. When there is loss of position sense and loss of a sense of balance when walking, the condition is called diabetic pseudotabies. (This mimics a common finding in long-standing syphilis.) Autonomic neuropathies can result in decreased blood flow to the brain when standing (orthostatic hypotension) and can cause some people to pass out. Impotence, abnormal sweating (dyshidrosis), and diarrhea can also be due to autonomic neuropathies.

Arthropathies. Several forms of arthropathies (disorders of the joints) occur in diabetes. Osteolysis is erosion of the bone commonly affecting the long bones of the feet and hands. This erosion can cause swelling of the fingers and toes and weakening of the bones. Osteoporosis is the loss of bone substance. It occurs much more frequently in women than in men, and there is an increased incidence in individuals with diabetes. Lifelong measures such as diet, regular exercise, and the use of estrogens at menopause can make a tremendous difference in prevention of this potentially devastating disorder.

Charcot joints are joints destroyed due to small fractures of the bone as a result of nerve damage to the joints. Diabetes can lead to a reduction of the blood flow in the small vessels to bones. Charcot joints are generally found in the ankles and feet. At advanced stages, the arch of the foot can collapse, which leads to marked difficulty in walking and a "rocker's sole" appearance on the bottom of the foot. With decreased sensation over the bottom of the feet, ulcerations and calluses can form. Therefore, attention to foot care is very important in diabetes.

Due to problems with the blood supply, nerve damage, and impairment of the immune system, infections can easily occur in individuals with diabetes. Osteomyelitis is infection of the bone and can easily be caused by objects such as pins which the patient with foot numbness steps on unknowingly. Adhesive capsulitis is the formation of scar tissue around the joint capsule. This will decrease the motion of a joint. The most frequently affected joints are the shoulders. In most cases, adhesive capsulitis can be treated with therapy and injections with good results. In a large study, 11% of diabetic patients had this disorder, and another study showed that 25% of patients with adhesive capsulitis were diabetics.

Connective tissue disorders can be specifically related to diabetes. Hyperuricemia (elevation of uric acid) and gout were initially thought to have an increased incidence with diabetes, but this assumption has been refuted. In contrast, diffuse idiopathic skeletal hyperostosis has increased incidence with diabetes. This is deposition of bone substance over the spine and almost looks like wet sand flowing down a castle wall. It is usually asymptomatic despite having striking x-ray features.

Flexion contractures occur much more commonly in individuals with diabetes. This condition may be due to decreased removal of skin collagen in diabetes compared to the increased synthesis of collagen that occurs in scleroderma. Scleroderma is a systemic connective tissue disorder consisting of tight skin and various degrees of internal organ involvement. A more serious variant of scleroderma is called progress systemic sclerosis. If the kidneys, lungs, or heart are involved, progressive systemic sclerosis can be fatal.

Dupuytren's contractures begin as nodules over the palms of the hands and then result in decreased movement in contracture of the fingers. They can also involve the feet. The "waxy-hand syndrome" (cheiloarthropathy) results in decreased motion of the joints, primarily in the fingers and toes. In this condition, feet and hands can develop tight skin that feels firm and waxy. A simple screen test of this disorder, also known as limited joint mobility syndrome, is to have the patient place both hands on the table, palms down with the fingers fanned. The entire surface of the fingers makes contact in normal persons.

Problems with skin, muscle, and tendons. According to one study performed by Rosenbloom, patients who had been diabetic an average of 16 years with the presence of stiff joints also had an increased incidence of eye and kidney damage.

Tenosynovitis is the formation of nodules over the sheaths that go around the tendons in the fingers and toes. There is an increased incidence of nodule formation of the tendon sheaths in individuals with diabetes. This can result in what is known as a "trigger finger" or "catching of the digits" (in toes or fingers) on movement. Beginning in the elbow, the tendon runs to the palm where it branches out into each finger, ending at the tip. Each branch of the tendon is surrounded by a sheath which runs from the base to the tip of each finger. In tenosynovitis, when the finger is bent, nodules (located in the palm of the hand) may catch on the sheath, causing the finger to be locked in place. Hence the term "trigger finger." The finger can be straightened by using the other hand to pull the finger forward; however, this is painful. The condition is treatable with finger exercises, steroid injection, or surgery.

Finally, circulated antibodies or immunoglobins directed toward different structures are increased in type II insulin-resistant diabetes mellitus. This type of diabetes is due to antibodies directed against the insulin receptors, resulting in increased glucose. There has been an association of this disorder with systemic lupus erythematosus; Sjogren's syndrome (mainly manifested by dry mouth and dry eyes); and progressive systemic sclerosis (marked skin tightness and potentially devastating involvement of internal organs such as kidneys, lungs, or heart). Progressive system sclerosis is a more serious, possibly fatal variant of scleroderma, which is mentioned above.

The treatment of arthritis includes rest, which is particularly important in rheumatoid arthritis and systemic lupus erythematosus. The use of hot and cold packs (thermotherapy) can be very helpful in decreasing pain and assisting with motion exercise. Protective splints can be very helpful with active arthritis.

Numerous medications are used to treat arthritis. Analgesics such as Tylenol decrease pain. Nonsteroidal, anti-inflammatory medications such as aspirin, Motrin, and Voltaren decrease swelling and pain. Disease-modifying agents, such as gold, can be very helpful in patients with rheumatoid arthritis. Such agents delay or prevent severe bone destruction and decrease pain and swelling. Urate-lowering agents are used to decrease the production of uric acid, which leads to gout. Steroids are used for treatment of lupus, vasculitis (inflammation of the blood vessels), and in certain types of arthritis. Steroids should be carefully used, particularly with diabetes. Some surgeries can prevent severe complications from occurring (e.g., tendon ruptures), but they are generally considered as a last resort.

It is important for patients with arthritis and diabetes to be aware of the interactions of medications. Low-dose aspirin has a mild glucose-lowering effect; larger doses of aspirin have a glucose-elevating effect. Oral hypoglycemics can raise blood levels of aspirin, potentially leading to overdosage. Aspirin overdose can lead to complications such as ringing in the ears and stomach pain. Nonsteroidals interact with oral hypoglycemics by increasing their glucose-lowering effect. Steroids increase glucose and can disrupt diabetes control. Finally, antigout medications can interact with oral hypoglycemics to lower the serum glucose, leading to hypoglycemic reactions in some people. Arthritis medications can also be a problem with urine testing in individuals with diabetes. Aspirin and nonsteroidal anti-inflammatory medications can cause false-positive results for glucose and ketones.

This has been a very brief overview of interaction of diabetes and arthritis. If one does develop arthritis as a result of or simultaneously with diabetes, many things can be done to assist with care, such as exercise programs, rest, and attention to foot care including proper shoes, and prompt treatment of infections of bones and related structures. Medications can be helpful in controlling symptoms and decreasing pain. Everyone should remember that some medications can interfere with treatment of diabetes. Although not highly recommended, surgery can be helpful in some instances. It is important that one have a detailed discussion with a doctor if experiencing both of these disorders because of the interactions between treatments. With 40 million Americans with arthritis and 14 million Americans with diabetes (*some report an estimate of 16 million as of this writing*), I am sure some people do have both disorders.

For more information, interested persons may contact the American Diabetes Association, the Arthritis Foundation, or a doctor. I will be more than happy to answer any questions if you would care to write me at 2751 Virginia, Suite 2E, Shreveport, LA 71103.

Diabetes and Yeast Infections

Diana W. Guthrie, Ph.D., FAAN, CDE

Dr. Guthrie is a professor at the University of Kansas School of Medicine-Wichita. She has a doctorate in philosophy and social change, and works in behavioral psychology. In addition, Dr. Guthrie has her own diabetes clinic.

Yeast infections, usually Candida, cause a terrible itching. Women who have a change in the Ph of the vaginal tissues are more susceptible to a yeast infection. A yeast infection is accompanied by a yellow or white cheesy discharge which is usually odorless (most other vaginal infections have an odor to the discharge). This type of infection is most likely not sexually transmitted. When the blood sugar is high, there is a greater chance for this and other vaginal infections to occur. When a vaginal infection occurs, there is a greater chance that the blood sugar will go higher than it presently might be. Pain on intercourse is also likely to occur.

In a study of 203 women with diabetes, Candida albicans was isolated from 12.8% of all patients. This disease showed a significant association with the woman who had vaginal and external vaginal itching. In the particular population studied, of all the yeast infections identified, Candida glabrata was found in 50% of the cases and Candida albicans next (36.1% of the cases).

Treatment in the United States has more recently become easier to obtain. Antifungal medications are now available in over-the-counter preparations in creams or suppositories. A diabetic must be wise in choosing an over-the-counter preparation. First, blood glucose levels must be normalized as much as possible. Second, if the recommended treatment time (i.e., 7 days) does not bring the desired results, a physician must be consulted. If the infection is quite severe from the start, it is better to consult a physician and obtain the proper cultures before starting the treatment so that the specific organism(s) is(are) found. It is possible that more than one organism is responsible for the vaginal infection. And third, prevention is best. This means cleanliness including good personal hygiene (i.e., wiping from front to back); blood sugar control; and completing the full length of treatment (i.e, if treated, the suppositories or creams must be used for the full 7-day course of treatment, not just until the symptomatic itching and discharge go away).

Fruits and vegetables, exercise, and adequate rest should be included as part of the daily lifestyle, and drinking plenty of fluids (preferably water) is a must. Other recommendations are the wearing of cotton rather than nylon underwear. Tight clothing appears to aggravate the itching and also prevents drying air from reaching the infected area.

Therefore, one should avoid wearing tight jeans or other tight clothing, especially those made of tightly woven fabric. Douching is more harmful than helpful. One should not use douches unless recommended by the health professional. Soap and water is better than the use of a feminine hygiene spray. Safe sex must be practiced, especially if there is more than one partner. Finally, if the blood sugars are out of control, there will be a greater chance that a woman will develop a yeast infection or other types of vaginal infection.

There is also a greater chance that a vaginal infection will occur if a person is pregnant, taking oral contraceptive drugs, or menopausal. All of these occurrences lead to the possibility of a change in the Ph of the vaginal tissues, so dietary intake is very important, even though a specific approach to dietary intake is questioned by some. Again, prevention is the best approach. [*Editor's Note: One reviewer is familiar with some treatments with a 3-day course.*]

Hypoglycemia and How to Deal With It

Ed Bryant

Note: This section deals with a problem rehabilitation professionals may well encounter directly and suddenly in working with their blind diabetic clients. Readers may wish to note especially the suggestions for "first aid" which follow.

A "hypoglycemic reaction," also called an insulin reaction, insulin shock, or low blood sugar reaction, occurs when blood glucose drops to a point at which the diabetic becomes confused and disoriented. By definition, hypoglycemia is "low blood glucose" (described by many health professionals as any blood glucose level below 60 mg/dl), and it can affect both insulin-dependent and non-insulin-dependent individuals, though type I diabetics are more at risk.

To maintain good health, a diabetic must control both extremes by monitoring blood sugar levels and adjusting diet, exercise, oral medications, and insulin to keep those numbers in the normal range. It is not always easy to do these things, and sometimes working hard to keep sugars down results in allowing them to dip too low.

Prevention is the best way to treat a low blood sugar reaction. Though the personal "threshold" varies and some people can function at levels that would have others disoriented or unconscious, if sugars stay up around 80 to 120 mg/dl, a hypoglycemic reaction won't happen. Although there is some argument over exactly what is an appropriate "normal" for a diabetic with good control, the point is to provide a healthy range, while ensuring a margin of safety against "hypos." "Tight control" doesn't mean continuously staying below normal range.

One should not just wait for symptoms of a "low"--all that shakiness, sweatiness, and confusion--to indicate the approach of trouble; too often a reaction comes on without much warning. Frequent blood glucose monitoring is the best way to warn of impending hypoglycemia. By observing patterns of low blood sugar, by learning how much one's body needs, a diabetic can make the changes necessary to prevent a reaction. Although some can function perfectly well with their blood glucose in the low 60s, meters are imperfect--there is a 10% "fudge factor" either way, and an indicated "60" may in fact be closer to a very unsafe "54." To be safe, sugars should be kept in the normal range.

Although every effort should be made to prevent hypoglycemia, almost all diabetics, especially those who use insulin, will occasionally experience a reaction. Common causes include straying from the prescribed meal plan, taking too much insulin or oral medication, not eating the proper amount at the proper time, or doing vigorous exercise. Sometimes a low comes on for no apparent reason at all. Alcohol and certain drugs (certain sedatives, sleeping pills, and the "beta blockers") can also lower blood sugar and bring on a reaction. Diabetics practicing strict tight control and holding to a low blood glucose level increase their risk of hypoglycemic episodes. Although the long-term benefits of tight blood glucose control are great, some individuals may need to relax the numbers a bit, trading higher glucose meter readings for an increased margin of safety. THE GOAL SHOULD BE TO USE THE TIGHTEST CONTROL THAT IS RIGHT FOR THE INDIVIDUAL.

Symptoms vary between people; each person must learn what signals the approach of "getting low." Studies suggest a diabetic's awareness of his or her hypoglycemia is a learned response, which can be taught and improved by more education. There's no substitute for a blood glucose meter, but intuitiveness (i.e., "When I feel like this, my blood is doing that") is a good line of defense. The old saying, "Know thyself!" makes sense here. Once a person recognizes the symptoms, he or she can take quick action to correct the condition.

If blood sugars have been quite high for some time, acting to bring them down quickly may produce some hypoglycemic symptoms--but a blood glucose meter can provide reassurance that they merely mean the body is trying to get used to the new lower level. The symptoms will pass.

Symptoms of low blood sugar reaction can be divided into two general stages. The first stage, usually occurring early in a reaction, includes symptoms such as shakiness, sweating, nervousness, fast pulse, dizziness, headache, and pale skin color. Symptoms may appear suddenly. The second, more advanced stage of hypoglycemia, includes mood/behavior changes, confusion, poor coordination, and difficulty in speaking. If a reaction seems imminent, an immediate snack is a reasonable precaution. Better safe than sorry.

Next to prevention, the best way to treat a low blood sugar reaction is to "nip it in the bud." To do so requires that a diabetic realize it is happening. Many individuals have learned to recognize a reaction by the way they feel. For example, I have learned to recognize that at the first sign of a low, I feel a kind of inner shakiness, although it is not physically visible to anyone around me. Although difficult to describe, it is a sensation I have learned and recognize as an early sign of low blood sugar.

Some people have "hypoglycemia unawareness" and cannot sense when a reaction is coming on, or even that a reaction is in progress.

There may be few initial symptoms, or they may fail to recognize them. By the time they manifest symptoms, these individuals may be too disoriented to help themselves. They should be particularly careful to keep to their insulin and eating schedules and to monitor themselves for low blood glucose levels. Some studies suggest a long period of *euglycemia*, normal blood glucose achieved by tight control, may restore some ability to perceive low blood glucose. When such persons experience a reaction, it may appear at the "second stage," with disorientation, confusion, or even loss of consciousness. A diabetic in this condition, although still conscious and able to swallow, needs a concentrated, refined sugar immediately. CAUTION: DO NOT FORCE ANYTHING INTO THE MOUTH OF AN UNCONSCIOUS PERSON!

At the first sign of a reaction, the person needs to put energy food into the body immediately. If he or she has consumed sugar to ward off a low (many of us carry glucose tablets for just that purpose) and the symptoms have cleared, food containing complex carbohydrates, such as milk, fruit, crackers, or a peanut butter sandwich, should be then taken. Glucose tablets, sugar cubes, and cake icing all act quickly, but they "burn off" quickly too, and unless they are followed by more substantial food, there is a risk the hypoglycemia will recur. The Diabetes Control and Complications Trial suggested that people who had experienced a reaction stood a 50% risk of another within 24 hours and a 25% risk of another in the next 24 hours. The complex carbohydrates in the foods listed above enter the blood more slowly than does refined sugar, but their effects endure, helping re-establish euglycemia, proper blood glucose level. Diabetics should resist the temptation to gorge in such a case. Eating is necessary, but if they overeat, they may find their blood sugar up above 300 or more. They should eat enough to re-establish euglycemia, then stop and wait for the shakiness to fade.

If the individual "misses the signals," and for whatever reason no action is taken to bring the blood sugars back up, the reaction will progress. The individual with diabetes may shake or sweat. When someone asks if something is wrong, the response may be, "There's nothing wrong," or "I'm all right." Having become confused, the person may ask the speaker to repeat things or may state that the question was not understood. A person undergoing a low blood sugar reaction may appear distant, meditative, unusually quiet, "in another world." He or she may stop conversing, or might respond very slowly to questions. Some may become uncooperative or belligerent, spewing obscenities at the offer of assistance. The person experiencing a low may seem intoxicated. Unfortunately, every year a few diabetics, thought by police to be drunk, are jailed overnight "for drunkenness." Before morning, their untreated low blood sugar reactions can lead to brain damage, even to death.

I strongly recommend that all diabetics wear medical information jewelry, either a bracelet or necklace, and carry a medical information card at all times. I wear a bracelet, and my card is in my wallet. Such information, available at most pharmacies, alerts law enforcement and emergency personnel that the bearer is a diabetic and is subject to low blood sugar reactions. Because hypoglycemia is easily, quickly, and inexpensively treated, wearing a medical ID might help prevent an expensive and unnecessary trip to the emergency room.

A person who has diabetes should inform friends and coworkers about low blood sugar reactions, relating symptoms and remedies, and telling friends and fellow coworkers, "When in doubt, give me sugar."

It is important never to use diet drinks, insulin, or "sugar-free" candy to combat a low blood sugar reaction! Sugar substitutes provide no benefit, and one of them, *aspartame*, slows the absorption of what sugar might be present. Candy bars containing chocolate and nuts should not be used either--unless nothing else is available--because they are too slow. Their high fat content slows absorption of their sugars into the blood. Honey, composed of two sugars, acts rapidly but may get messy if the individual is shaky and disoriented.

Many kinds of concentrated sugar products, developed specifically to combat low blood sugar reactions, are available over-the-counter in pharmacies. Many are pure glucose. I like Can-Am's "Dex-4" glucose tablet because they dissolve quickly in the mouth, and the container is easy to open. I take three or four of them to combat a reaction.

Such a dose should bring one out of a reaction to the point at which it is possible to eat some complex carbohydrates, more substantial food, as stated above. However, if there is no improvement after 15 to 30 minutes and there is still unawareness or unsteadiness, the diabetic should consume another three or four glucose tablets or another small tube of cake decorator's gel. Each person is different; one individual may require more or less glucose and time than another to come out of a low blood sugar reaction.

One inexpensive (and tasty) "insurance policy" against a low is Lifesavers! Five of these little candies add up to 12.5g of sugar and provide the same dose as three glucose tablets (though not quite as quickly absorbed). They're easily available, which can be a big advantage.

Another treatment can be granulated table sugar (sucrose). It is far more economical than over-the-counter glucose products and raises the blood glucose level nearly as rapidly. I am often asked how much table sugar should be taken for a reaction. As a general rule, if an adult is able to swallow safely, without choking, one heaping tablespoon (about 15 grams) of granulated (table) sugar should be given. Some individuals will come out of the reaction rapidly; others may take longer. If total awareness does not come in 15 to 30 minutes, it may be necessary to give another heaping tablespoon of sugar. And then, of course, as soon as the person is able, he or she needs to eat more substantial food containing complex carbohydrates as described above, to keep the reaction from recurring.

Another source of emergency sugar is cake decorating gel (icing). I purchased a small tube of Betty Crocker decorating gel and found it easy to work with. It weighed 0.68 oz (19 grams), with about 65% refined sugar solids, a combination of corn syrup and sugar, and the balance water. A small tube of decorating gel contains about 12 grams of solid sugar, ample to treat a low blood sugar reaction in most people. If one tube does not bring the person out of the reaction in 15 to 30 minutes, it may be necessary to use a second.

When a diabetic is unconscious due to a low blood sugar reaction, many physicians recommend an injection of glucagon, a prescription drug. It acts rapidly and causes the liver to release stored glucose directly into the bloodstream. After an injection, the individual should regain consciousness within 10 to 30 minutes. A lot of variation is to be expected since no two diabetics, and no two reactions, are the same.

After giving the injection, one should apprise the individual's physician of the situation. The glucose released after a glucagon injection burns off rapidly. To prevent recurrence, it is important for the diabetic to eat some food, especially complex carbohydrates. Glucagon may make some diabetics nauseated. Since there is a risk of vomiting, the patient's head should be turned to one side to guard against choking. Some individuals may need to wait 20 to 30 minutes after glucagon is administered before having any food. Incidentally, glucagon is expensive. In my area, it costs about $40 per prescription, but I recommend all individuals with diabetes keep glucagon emergency kits on hand. Glucagon keeps without refrigeration.

There seems to be no medical consensus regarding how much time should elapse before emergency help is sought. However, if a diabetic is not cognizant after two rounds of sugar or two injections of glucagon, emergency medical help should be summoned.

A client with diabetes walks a thin line between high and low blood sugar. To keep diabetes under control, he/she must follow the recommended diet and exercise and must take the proper dosage of medication on time. A diabetic should not become obsessive over tight control. The goal should be to use the tightest control that is right for the individual. Keeping to a schedule is the first line of defense. If and when a diabetic experiences a reaction, the best way to ensure safety is to know how to bring him/her out, to keep the tools close at hand (glucose tablets, cake icing, glucagon), and to tell families, friends, and coworkers what to do when the individual must have help from someone else. A hypoglycemic reaction is an emergency situation and should be treated quickly to restore normal blood glucose level. Professionals who serve people with diabetes should plan, prepare, and be rewarded through successful handling of crises. [*Editor's Notes: One reviewer stresses that it is important to re-check blood sugar 15-30 minutes after treatment, if a meter is available. If the reading is still below 70 mg/dl, one should repeat 15g of carbohydrate, and the individual may need protein or complex carbohydrate, depending on the time of the next meal. Another reviewer comments that hypoglycemia treatment for persons on acarbose requires use of glucose tablets or milk (lactose)--not sucrose--because of delayed absorption.]*

Diabetic Peripheral Neuropathy

NFB Diabetes Action Network

Neuropathy is a general term for physical damage to or impairment of the human nervous system. It has many causes and many symptoms. Because a long period of time with elevated blood glucose can damage nerve fibers, diabetes is one cause of neuropathy.

The human nervous system is enormously complex. The peripheral nerves carry information to and from the brain, connecting it with the rest of the body. These nerves can be motor, sensory, or autonomic. Motor nerves carry messages from the brain for the contraction of different muscles. Sensory nerves relay to the brain sensations of touch, temperature, position, and pain from the body's periphery. Autonomic nerves carry the brain's commands to organs such as the heart, the stomach, lungs, and liver.

The longer the nerves, the more likely they are to be damaged by long-term high blood glucose. The first part of a nerve to show damage is the part furthest away from the central nervous system (brain and spine). Once such damage occurs, problems appear at the nerve terminals of feet, lower legs, and hands.

Symptoms of peripheral neuropathy can include diminished tactile sensation, numbness, loss of reflex reaction, "pins and needles," and various types and degrees of pain. As neuropathy progresses, the symptoms frequently change. Caution: Diabetics experiencing neuropathy sometimes have other ramifications as well, and these have their own symptoms. Sometimes symptoms overlap, and diagnosis can be confusing. Diabetic *nephropathy*, kidney failure, can exacerbate neuropathy, due to the uremic toxicity of the condition. Other pain can be a symptom of undiagnosed orthopedic problems. If the individual experiences pain or abnormal sensations in hands, feet, or legs, he/she should consult a doctor.

Because diabetic neuropathy follows extended periods of hyperglycemia, its best prevention is good blood glucose management, tight control, with numbers down in the normal range. A healthy lifestyle, with plenty of exercise and careful attention to diet, helps too. Incidentally, the same tight control regime can help those with already established neuropathy. Although it is not clear exactly how it happens, experience shows that getting diabetes under control and keeping it there can, over several months, alleviate at least some of neuropathy's symptoms.

Individual symptoms are as varied as individuals, but the most common complaint is pain, and pain control becomes the single biggest challenge in dealing with established neuropathy. Doctors have prescribed aspirin, acetaminophen, and various other non-steroidal anti-inflammatory drugs, the anticonvulsants Dilantin and carbamazepine (Tegretol), and tricyclic antidepressants such as amitriptyline (Elavil), or a combination of vitamins B1, B6, and Glutamine, with varying results. Along with the drugs, some are prescribing capsaicin cream (Zostrix and its equivalents), a topical ointment originally formulated for arthritis pain. Others are investigating acupuncture, although not enough is known about it to say for certain if it works in such a case. Researchers are experimenting with aldose reductase inhibitors such as Sorbinil, but in the U.S., these are still in the laboratory stage.

There is a lot of disagreement over effective treatments for neuropathy pain. Each person swears by a particular remedy, having found and used what works in that case. One should, however, beware of extravagant claims for a single pill or technique; there are no "miracle cures." None of the pills and creams, moreover, are as effective in bringing relief as is getting your blood sugars under good control and keeping them there. It is not known just what mechanism causes neuropathy or even why some healing can occur, but it is established that the best chance for symptom improvement comes with long-term improvement in diabetes control. Although damaged nerves may heal in time, what has been destroyed will not regenerate. Good control is good medicine!

The main reason we, as human beings, have a pain reflex is that pain lets us know something is wrong in the affected area. If it hurts, we do something about it. With its biggest symptoms being pain (when nothing is present) and diminished sensation/numbness, neuropathy can seriously interfere with one's self-care of diabetes, especially care of the feet. Circulatory problems stemming from diabetes can lead to dry skin on the feet, with the risk of ulcers and lesions. Lacking normal pain reflexes, the individual with neuropathy may not be aware his or her feet are in trouble. Even stepping on a tack may be pain-free. This means otherwise treatable lesions are allowed to progress into severe infection, sometimes into gangrene. Amputation is a common result of this progression of events, and complications of diabetes account for the majority of non-traumatic amputations in the U.S. today. All diabetics need to inspect their feet frequently, but individuals with neuropathy need to be especially thorough.

Although there are many variations, the main rule being "Do what works for you," there are a number of non-medicinal ways people cope. One individual, who reported "burning feet" at night, slept with her feet uncovered and a fan blowing cool air on them. Many others cushion aching feet with thick, seamless hikers' socks, especially those made of cotton or of new materials such as Thorlo.

Some report that exercise brings temporary relief. Others use meditation-based relaxation techniques to help them manage. Another approach followed by many is to wear high-quality, properly fitting athletic shoes with good support, or support sandals such as Birkenstocks, along with the socks mentioned above.

Many individuals whose feet are affected by diabetic neuropathy are also dealing with circulatory problems and perhaps have a history of ulceration or even a partial amputation. Special therapeutic shoes with custom inserts or "extra-depth shoes" or several other shoe modifications, are covered by Medicare as durable medical equipment. These options should be discussed with one's doctor. Unexplained discomfort--whether it is pain or merely abnormal sensation--is a serious matter. It may indicate neuropathy, which may be from diabetes or may stem from some other condition. It is NOT an inevitable ramification of diabetes, but one shouldn't just "grin and bear it" either. A lot of different therapies and interventions bring relief to many individuals with diabetes. One should work to keep the best control possible, keep the doctor informed, and not lose hope.

Diabetic Gastroparesis

Gastroparesis, "delayed gastric emptying," is one of the more serious ramifications of diabetes. We tend to take the working of the stomach and intestines for granted until they stop working properly. The digestive tract is closely controlled by the brain, via the autonomic nerves.

Problems come with the development of neuropathy. Extended periods of time with high blood glucose or with the uremic toxicity that follows kidney failure can damage nerve fibers, and when the autonomic nerves are damaged, stomach function can become increasingly unpredictable. As with neuropathy, an individual may have mild to severe symptoms of gastroparesis.

Gastroparesis may cause early satiety (feeling "full" almost immediately after starting to eat), abdominal bloating, gastric pain, nausea, and vomiting. The person with gastroparesis may burp or vomit up food consumed many hours before--and find it nearly undigested. The nausea, vomiting, and dehydration may become severe enough to require hospitalization. Anorexia, unwillingness to eat, can become a factor. With so much frustration and difficulty digesting food, the person simply chooses not to eat rather than be sick all the time. This creates further problems with blood sugar control and may lead to malnutrition.

Gastroparesis alone is a double handful for anyone struggling to cope. When it follows diabetes, it can become far more serious. The "backbone" of diabetes self-management is good scheduling--but such scheduling assumes that food taken on time will be digested on time. The diabetic forever juggles food, insulin and/or oral medications, exercise, and time-of-day to optimize blood glucose level. The unpredictability of gastroparesis injects a new variable into the equation since the digestive system may function on time, late, or not at all.

Meals may be missed; oral medications may be undigested. The correct amount of insulin, taken with a meal may, throw the individual into hypoglycemia when the meal remains undigested. Compensating for expected difficulties, that do not then materialize, the diabetic may experience hyperglycemia.

The serious consequences of severe gastroparesis are a ringing argument for good, consistent diabetes self-management, adopted before such ramifications have the opportunity to develop. The Diabetes Control and Complications Trial (DCCT) proved that tight control of blood glucose radically diminished the likelihood of such complications as neuropathy, nephropathy, retinopathy, and gastroparesis.

Diabetes is a sneaky disease. Clients may do their best and still experience severe complications, or they may have developed the condition years before the DCCT, back when the field didn't know so much about good control. If they have gastric difficulties, they should talk to a doctor. Gastroparesis is just one of many conditions that can interfere with digestion.

If a doctor determines that a person has gastroparesis, a number of options are open, depending on the severity of the symptoms. Medications such as Metoclopramide, Bethanecol, Domperidone, Cisapride (Propulsid), and surprisingly, the antibiotic Erythromycin, bring some relief. Diet may need adjustment toward easy-to-digest foods.

Not enough is known about gastroparesis or about the neuropathy that produces it. Future studies should provide better tools to deal with this ramification. We do know that diabetics who get their blood sugars under good control and keep them there often see a lessening in the severity of complications. It is never too late to improve control.

Diabetes and Men's Sexual Health

Ed Bryant

One of the most feared complications of diabetes, erectile dysfunction, commonly known as impotence, is also one of the most treatable. More than 50% of men with diabetes may experience this complication, but over 95% of cases can be successfully treated. With proven treatment available, an individual experiencing this problem does have options. It isn't something he--or any other man--or his partner--should have to live with.

Many men do not feel their difficulties, especially with sexual performance, are a fit subject to discuss with their partners. They couldn't be more wrong. To avoid making things worse, a man needs to move beyond the old idea that the sex act is something he does. He is part of a relationship, and what interferes with one, affects both. A man's partner is equally involved.

Achieving and sustaining an erection requires interaction between the neurological, arterial, hormonal, and psychological functions of the body. Proper hormonal balance, normal sex drive and emotional make-up, functioning nerves and blood vessels, and healthy penile tissue are all required. Libido, the interest in sexual activity, and potency, the ability to perform, must both be present. Several different sets of nerves are involved. Erection is a function of the parasympathetic nervous system, but orgasm and ejaculation are controlled by a different set of nerves, the sympathetic system. Both orgasm and ejaculation can occur without erection.

"Erection is a hydraulic phenomenon that occurs involuntarily," says Arturo Rolla, M.D. of Harvard University, School of Medicine. "Nobody can will an erection!" Anything that limits or impairs blood flow can interfere with the ability to achieve erection, no matter how hard a man tries.

Although sexual vigor declines with age, a man who is healthy, physically and emotionally, is able to produce erections and enjoy sexual relations, regardless of his age. Impotence is not an inevitable part of the aging process.

On occasion, any man may experience the inability to achieve or sustain an erection. Such transient episodes are common and may be attributed to illness, fatigue, stress, etc. The occasional inability to perform, however traumatic to both partners, is normal.

Repeated inability to achieve and sustain an adequate erection can be caused by anything that affects a man, psychologically or physically. Psychological, or "psychogenic," impotence can follow major life changes, stressful events, or even the fear of becoming impotent. The physiological changes associated with fear can cause erectile dysfunction. When an individual discovers the source of his difficulties is not physical--that it is due simply to fear of ramifications--sexual function is usually restored. But to tell the difference between physical and psychogenic impotence, and to make any progress against it, requires that he TALK about this sensitive issue--with his partner, his physician, and ideally, with a urologist specializing in male impotence.

Sexual dysfunction can contribute to psychological problems such as feelings of inadequacy, frustration, loss of self-esteem, and despair. Strained relationships with partners may result. It is important for men to discuss the problem with their partners and to promptly seek medical attention. Many may find counseling helpful.

Diabetic impotence is generally a result of the blockage of blood vessels responsible for erection, damage to the nerves that dilate those blood vessels, or a mixture of the two. In some cases, re-establishing good glycemic control may decrease the impotence, though permanent damage to nerves and vessels may not be reversible.

A man can decrease his risk of impotence by carefully controlling his diabetes. Poorly controlled diabetes and high cholesterol increase the chances of vascular complications, especially vessel blockage, which may lead to erectile dysfunction or to other circulatory problems. Men with diabetes should exercise regularly and avoid nicotine and alcohol since smoking causes constriction of the blood vessels and contributes to arterial blockage. Good health practices help men prevent impotence.

Impotence, the chronic inability to have and sustain an erection adequate for sexual intercourse, may be a symptom of a more serious disorder. Seeking prompt medical help for sexual dysfunction can lead to early diagnosis of other problems. Identification of the source of impotence can point the way to prevention of strokes, heart attacks, and other life-threatening illnesses. Learning is the first step to recovery, especially when fear is the culprit.

Regardless of the cause, if a man does not have or cannot sustain erections adequate for vaginal penetration, and the problem continues over a period of 4 to 5 weeks, he should recognize a problem exists and seek medical help. He should avoid delay since erectile dysfunction doesn't just go away.

In treatment of impotence, the choice of doctors is most important. Among the best choices are those practicing at centers specializing in erectile dysfunction, urologists who subspecialize in the treatment of impotence, and other physicians specifically trained in this field. Most people's first contact is with their family doctors. They should ask that first physician for a referral to a medical professional who is particularly familiar with this disorder. Local hospital referral services may keep lists of such experts who practice nearby.

After the interview and physical exam, the doctor will determine whether the erectile dysfunction is psychological or physical in nature. Where diabetes is present, a vast majority of instances of erectile dysfunction have a physical cause. But based on examination and interview, the doctor may determine the cause to be psychological, and refer the man to a qualified health professional specializing in psychologically induced erectile dysfunction. This may be a psychiatrist, psychologist, sex therapist, or marital counselor.

Troy A. Burns, M.D., National Medical Director of The Diagnostic Centers for Men, in his *Getting Help: A Patient's Guide for Men with Impotence* (1994), published by Integrated Medical Resources, of Lenexa, KS, reports that an old at-home test for erectile activity during sleep (the lack of which would suggest physically caused impotence) ". . . was the postage stamp test. The patient was instructed to wrap several stamps snugly around his penis at bedtime. If the stamps had perforated by the time he awakened, some penile tumescence probably occurred!" Of course, more sophisticated tests are used today.

Impotence is sometimes a side effect of medications prescribed for other disorders. Such medications include some anti-hypertensives (diuretics and beta blockers), ulcer medications, the heart medication Digoxin, antihistamines used for allergy control, antipsychotics, commonly used tranquilizers such as Diazepam, certain antianxiety drugs, certain narcotics, anticholinergics, tricyclic antidepressants, and many illegal drugs. Elavil and other tricyclic antidepressants sometimes used to treat the pain of neuropathy, can cause, trigger, or aggravate impotence. A person's unrelated disorders may also contribute to the problem since over-the-counter medications, including certain eye drops and nose drops, have been associated with erectile dysfunction.

Any man who experiences erectile dysfunction and is using other medication should discuss the problem with his doctor. By adjusting the dosage of current medication(s) or by switching to alternates, erectile dysfunction may be alleviated. A doctor or pharmacist should provide information about side effects, and it is important to read the package insert in the container. One should always consult a physician before discontinuing any medications.

Much is now known about the causes and treatments of erectile dysfunction, and impotent men should be aware of their various treatment options. Although surgery is one choice, 95% of cases are resolved by non-surgical means, and the National Institutes of Health recommends trying non-surgical treatments before more invasive methods. All options should be considered, but the man's personal preferences--and those of his partner--are vital in the choice of treatment. For the purpose of discussion, I've divided treatments into three categories: medications, external mechanical devices, and surgery.

Medications

External vasodilators improve blood flow. When diagnosis indicates a problem in the vascular system, particularly arterial insufficiency, externally applied vasodilators (ex. nitroglycerine ointment) can be used to dilate arteries, improving blood flow into the penis. Commonly used in treatment of high blood pressure and associated heart disease, the ointment is applied to the penis to increase penile arterial flow and improve erections. The most notable side effect is that it may give the female partner headaches since it is absorbed into the bloodstream through the vagina. To prevent this, the man should use a condom. Another topically applied vasodilator, Minoxidil, was found to have fewer side effects and be more effective than nitroglycerine cream. Although some cases of erectile dysfunction respond well to this kind of therapy, the effectiveness of vasodilator products has not yet been determined by the scientific community.

Yohimbine therapy shows promise. Yohimbine medication comes from the bark of a tree that grows in Africa and India. The extract, long used as an aphrodisiac and folk remedy for impotence, has proved effective in some impotence cases. It is not known exactly how the medication works, but it seems to affect the central nervous system by suppressing nerves that normally restrict erection. It's thought that yohimbine may also increase libido (desire) in some men. The few side effects of yohimbine tablets can be easily alleviated. Many doctors prescribe this therapy for cases of very mild, physically caused dysfunction or for psychological impotence. This therapy does have merit and should be considered.

Many sources report that penile injection therapy has an estimated 80% rate of success. Injected directly into the penis, the medication produces erection by relaxing certain muscles, increasing blood flow into the penis, and restricting outflow. The therapy has disadvantages, such as risks of infection, pain, and scarring (fibrosis) in the penis, and it may create "priapism," a prolonged, painful erection lasting 6 hours or more (although reversible with prompt medical attention). The most popular medication is Upjohn Corporation's Caverject, the first to be approved for such use by the FDA.

Drug combination injection therapy, which uses combinations of drugs, has been developed and is proving to be a good "fallback" for individuals who experience difficulties with Caverject alone. "About 15% of all individuals who try therapy with Caverject experience significant pain at the injection site," says Troy A. Burns, M.D. "For these 15%, a combination of Caverject, Papaverine, and Phentolamine produces less or no pain."

Alternatives. The MUSE System is a non-invasive alternative to penile injection. The user dispenses his medication (alprostadil/Caverject) with an eye-dropper-like applicator, directly in the urethra. No needles are required. FDA approval of the device has been awarded.

"Rejoyn" is an inexpensive, non-prescription alternative to the many vacuum-actuated devices described below. Described by its manufacturer as a "support sleeve," it does not "cause" an erection, but rather supports the flaccid penis as if it were erect.

External Mechanical Devices

This category of treatments for erectile dysfunction includes external vacuum therapies, non-invasive external mechanical devices that produce painless erections by causing blood to flow into the penis while constricting outflow of blood. Such devices imitate a natural erection, and do not interfere with orgasmic experience. External vacuum therapy mechanisms are approximately 90% successful in causing and sustaining an adequate erection. All are portable, cost about $400 - $450, and may be covered under most insurance plans.

The vacuum constriction device consists of a vacuum cylinder, various sizes of tension rings, and a vacuum pump, either hand-operated or electric. The penis is placed in a cylinder to which a tension ring is attached. Air is evacuated from the cylinder by means of the pump, creating a vacuum which produces the erection. The cylinder is removed, leaving the tension ring at the base of the penis to maintain the erection.

Most insurance companies do provide coverage for this type of mechanism.

Vacuum therapy devices have a few minor disadvantages. One must interrupt foreplay to use them. THE TENSION RING MUST BE REMOVED AFTER SUSTAINING THE ERECTION FOR 30 MINUTES, TO PREVENT PENILE BRUISING. One must use the correct-size tension ring and make sure not to fall asleep while wearing one of these devices. Although considered to be basically pain-free, initial use may produce some soreness. Such devices may be unsuitable for men with certain disorders related to blood clotting. In general, vacuum constriction devices are successful in management of long-term impotence, and they enjoy wide physician acceptance. "At our institute," says Troy A. Burns, M.D., founder and medical director of The Diagnostic Centers For Men, "each doctor regularly prescribes such devices 20 to 30 times a month. Complaints are rare; very rarely do we have anyone bring them back. They usually work really well."

Surgical Treatments

There are many other less invasive and less expensive options, and surgery should be considered only after all others have proved unsatisfactory. Of the two kinds of surgery performed, one involves implantation of a penile prosthesis; the other attempts vascular reconstruction. Less than 5% of impotent men may benefit from vascular surgery. Expert opinion about surgical implants has changed during recent years; today, surgery is no longer so widely recommended. Even though it is 90% effective, surgery is expensive in both monetary and human terms, but it is one available option for impotent men. The decision to have or not have surgery is one that should be made by the man and his sexual partner.

Companies that market surgically implanted prosthetic devices sell only to hospitals and physicians and will not provide the selling price to consumers. Through research, I have found that the malleable prostheses cost about $1,400, and inflatable devices cost about $4,000. If the man elected to undergo surgery and fees were totaled (surgical, operating room, and the markup on the prosthesis), the cost would be about $9,000 for the malleable and about $13,500 for the inflatable device. These prices reflect rates in central Missouri and should not be considered national averages. The main risk associated with penile surgery is infection. Although every attempt is made during the procedure to prevent infection, it can develop and may force removal of the prosthesis. As with all invasive procedures, there may be some pain, bleeding, and scarring. I also note that the device might fail to work properly and may have to be removed. If for some reason the prosthesis or parts become dislocated, surgical removal may also be necessary. With a general success rate of about 90%, any of the devices will restore erections, but they will not affect sexual desire, ejaculation, or orgasm.

Prostheses: Many different types of penile prostheses are available in three categories: rods, inflatable prostheses, and self-contained prostheses. Semi-rigid or malleable rods are the simplest and least expensive. Their main disadvantage is that the penis remains constantly erect, which may cause problems with concealment.

Inflatable prostheses are complex mechanical devices that imitate the natural process of erection. Parts are inserted surgically into the penis and scrotum, and activated by squeezing. When erection is no longer desired, a valve on the pump is pressed, and the penis becomes flaccid. Disadvantages include risk of mechanical breakdown or leakage. Fully inflatable devices are the most expensive of the three categories because of the complicated surgery necessary to implant the parts. Self-contained single unit prostheses are similar to the inflatable types, but more compact. The entire device is implanted into the penis. When erection is desired, the unit is activated by either squeezing or bending, depending on which of the two types of self-contained prostheses is used. Some of the mechanical types have been known to fail during intercourse; the inflatable device can sometimes be difficult to operate.

All penile implants will produce erections suitable for intercourse. When decisions are being made regarding the kind of surgery, other factors should be considered. According to Bruce A. MacKenzie in *Impotence Worldwide* (Volume 7, No.2), purpose is only one of several elements considered when selecting an implant. MacKenzie says, "To those who wish to simulate nature to the furthest extent, then a fully inflatable would be their choice; for those who wanted something relatively simple, ready to use, with lower cost and 1 day less in the hospital, their choice would be the hinged or malleable; to those who wanted a compromise between the two--a hybrid--they would choose a self-contained; and for those who wanted the least expensive (low end of the line)--the semi-rigid would fit the bill."

Vascular reconstructive surgery for impotence uses highly sophisticated techniques and equipment to physically correct the underlying causes of impotence in the penis. The surgeon may attempt reconstruction of the arterial blood supply or remove veins when the cause is due to leakage. Less than 5% of men with erectile dysfunction have such surgically treatable impotence!

When quality of life is affected by erectile dysfunction, a man should seek a physician's help, preferably a carefully chosen specialist. He should not wait for his doctor to ask him about sexual functioning but should talk about it freely. Nothing is cured by silence. He should talk about it with his partner/spouse too since she is equally affected by his condition. The man should remember they are both involved, so she is integral to the relationship and deserves complete honesty. Relationships are solid only when couples consider each other's feelings, so men should make it a point to communicate with their partners.

Companies That Market Impotence Therapy Systems

American MedTech Corporation, 2720 Nevada Ave., New Hope, MN 55427; telephone (800) 524-8014. They offer "Rejoyn," an over-the-counter impotence "support sleeve."

Encore Medical Products Centre, 2300 Plantside Drive, Louisville, KY 40299-1928; telephone (800) 221-6603. They offer vacuum constriction devices.

The Impotence Information Center, American Medical Systems, P.O. Box 9, Minneapolis, MN 55440; telephone (800) 843-4315. They offer prosthetic devices.

Mentor Corporation, 5425 Hollister Ave., Santa Barbara, CA 93111; telephone (800) 235-5731. They offer both vacuum constriction and prosthetic devices.

Osbon Medical Systems, P.O. Box 1478, Augusta, GA 30903; telephone (800) 438-8592. They offer both vacuum constriction and prosthetic devices.

Pos-T-Vac, P.O. Box 1436, Dodge City, KS 67801; telephone (800) 627-7434. They offer vacuum constriction devices.

VIVUS, Inc., 545 Middlefield Road, Suite 200, Menlo Park, CA 94025; telephone (415) 325-5511. They offer their non-invasive MUSE delivery system for the drug alprostadil (Caverject).

Resource List of Information and Services

American Association of Sex Educators, Counselors, and Therapists (AASECT), P.O. Box 238, Mount Vernon, IA 52314. For a list of certified AASECT members in your state, send a self-addressed stamped envelope.

The Diabetes Action Network of the National Federation of the Blind, 811 Cherry Street, Suite 309, Columbia, MO 65201; telephone

(573) 875-8911. They offer free copies of articles and other information pertinent to diabetes and its ramifications.

The Geddings Osbon, Sr. Foundation, Impotence Resource Center, P.O. Box 1593, Augusta, GA 30903; telephone (800) 433-4215. They offer two booklets free on request (single copies, print or audiocassette) titled *Impotence: A Woman's Perspective* and *The Male Treatment Guide*. They also offer physician referrals.

Impotence Institute of America, 10400 Little Patuxent Parkway, Suite 485, Columbia, MD 21044-3502; telephone (800) 669-1603 or (410) 715-9605. They publish a periodical titled *Impotence Anonymous*.

Integrated Medical Resources, Inc., 8326 Melrose Drive, Lenexa, KS 66214; telephone (913) 894-0591. They publish *Getting Help: A Patient's Guide for Men with Impotence*, by Troy A. Burns, M.D.

National Kidney and Urological Diseases Information Clearinghouse, Box NKUDIC, 9000 Rockville Pike, Bethesda, MD 20892. They publish a comprehensive bibliography on impotence free upon request, *Impotence: Patient and Professional Materials*.

Cardiovascular Health: Bypass May Be Better for Your Client

Individuals with severe coronary artery disease face the risk of vascular blockage, which can lead to angina, weakness, and heart attack. Traditionally, these patients have received one of two treatments: CABG (bypass surgery) or PTCA (percutaneous transluminal coronary angioplasty, "balloon angioplasty"). Diabetes is a major cause of heart disease, and enough individuals have undergone one or the other procedure to form a statistical picture of these procedures' effectiveness.

PTCA uses a catheter, which is inserted into the obstructed vessel from an entry point in the groin and inflates like a balloon to dilate the blocked vessel at the point of obstruction, allowing blood to flow past the blockage. CABG, a major operation, involves opening the chest and providing a new channel, or "bypass," for the blood flow. Both treatments alleviate the effects of coronary artery disease, but neither alters the natural course of the disease.

One might expect the success rates of the two procedures to be about the same, or for the less invasive PTCA, to be better. Beginning in August, 1988, the Bypass Angioplasty Revascularization Investigation (BARI), a major study sponsored by the National Heart, Lung, and Blood Institute of the National Institutes of Health, compared the effectiveness of the two procedures. Results were surprising.

Using "mortality after 5 years of follow-up" as a yardstick, the BARI study found that for non-diabetic patients, the procedures scored equally, with a 9% mortality rate. For individuals on insulin or oral hypoglycemics (type I or type II), the 5-year mortality rate following PTCA, the less invasive procedure, was 35%, and the rate for CABG, bypass surgery, was 19%. Although the higher overall mortality rate from diabetic heart disease was not unexpected, the excess mortality with balloon angioplasty was not anticipated.

Results of the study indicate that bypass surgery should be the preferred treatment for individuals with diabetes on insulin or oral medications who have multivessel coronary artery disease and need a "first coronary revascularization" (first-time PTCA or CABG). Because the Centers for Disease Control report that in 1989, about 48% of all diabetes-related deaths had major cardiovascular disease as the underlying factor, these findings are expected to have major impact.

Patients were eligible for the BARI trial if they had coronary artery disease with a 50% or more luminal obstruction (as measured by calipers) in at least two of the coronary vessels supplying two or three major coronary territories. They had to have clinically severe ischemia (measurable obstruction to blood flow), and no prior revascularization. Patients were ineligible if, for example, they had insufficient angina or ischemia, required emergency revascularization, had left main stenosis of 50% or greater, had a noncardiac illness expected to result in limited survival, primary coronary spasm, or a poor-quality angiogram (x-ray examination of the circulatory system). All patients accepted for the test received "risk factor modification": help with smoking cessation, appropriate exercise, and diet.

Findings of the BARI study were reviewed on September 13, 1995 by the Data and Safety Monitoring Board, a panel of PTCA experts, cardiovascular surgeons, clinical cardiologists, biostatistics experts, and ethics specialists. The Board concluded that the differential results of the two treatments, and the unfavorable mortality for individuals on insulin or oral hypoglycemics were unlikely to be due to chance. The Board recommended to the National Institutes of Health that physicians, other health professionals, and the public be promptly informed of the results.

In summary: The BARI study was a careful comparison of the results of two medical procedures frequently used in response to multiple coronary artery disease. Many "endpoints" were investigated, including patients' anginal status, number of diseased vessels, functional status, quality of life, gender, age, race, and presence/absence of diabetes. Although the study considered many issues, its findings for individuals with diabetes were particularly significant. The study strongly suggests that if one is (a) diabetic, using insulin or oral hypoglycemic agents (sulfonylureas); (b) suffering from multiple coronary artery disease; and (c) at the point of needing a first revascularization, he or she will probably fare better with CABG, bypass surgery, than with PTCA, balloon angioplasty, as an initial treatment.

Anyone who has evidence of coronary artery disease, with or without a prior PTCA or CABG, needs to be under close physician monitoring to reduce known risk factors aggressively through such measures as smoking cessation, appropriate control of blood pressure and serum cholesterol, and optimal control of diabetes.

Author's note by Ed Bryant. I've had bypass surgery. Several doctors have told me the best way to determine if you have coronary artery disease is with a "routine exercise treadmill test." While the patient works out, electrical instruments measure heart rate, heart rhythm, EKG, and blood pressure; and the doctor will note any other symptom which is evident. Added together, all the test data give a good picture of the state of one's heart.

One can have a normal pulse and still have significant coronary artery disease. Individuals with and without diabetes can have normal EKGs too, even in the early stages of a heart attack. One physician told me, "The absence of electrocardiographic abnormalities does not preclude the presence of significant heart disease."

My doctors said that if people have multiple risk factors like high cholesterol, hypertension, smoking, cardiac arrhythmia ("heart murmur"), or a family history of heart trouble (another is the presence of diabetes), they ought to have periodic treadmill checks to see how their hearts are doing. If one has had diabetes for 20 years (IDDM or NIDDM), he or she could likely benefit from this test. If heart disease is discovered soon enough, medical intervention can make a difference.

Diabetic Ketoacidosis

NFB Diabetes Action Network

Dorland's Medical Dictionary defines ketoacidosis as an acid condition of the blood marked by the presence of ketones, as in diabetic ketoacidosis (DKA). This dangerous condition can occur in individuals who have had very high blood sugars (hyperglycemia) for an extended period of time.

Remembering that insulin allows the body to digest and utilize glucose, the reader should understand clearly that an untreated type I diabetic with long-term high blood sugar, is literally starving to death, no matter how much food he or she may consume. Without the means to process the glucose so overabundant in the blood, the body begins consuming stored fat and muscle. When the body begins burning its stored reserves, ketones are produced. Ketone production is normal, especially during exercise or weight loss dieting, but the healthy body excretes the ketones it produces, so there is no harmful build-up. Diabetes, however, changes the rules.

The prolonged high blood glucose of untreated IDDM impairs the kidneys' normal ability to excrete ketones. Serious problems follow, when unexcreted ketones, products of fat and muscle metabolization, build up in blood already saturated with sugars. Such a condition can cause diabetic coma, and without immediate medical intervention, can cause death.

Although people with anorexia, hunger strikers, and people marooned for long periods without food or water or facing dehydrating illness can experience ketosis (ketone build-up in the blood), DKA, the one-two punch combination of ketosis and high blood acidity from sustained elevated blood glucose, is particularly deadly to the diabetic. Ketoacidosis takes time to develop and is one more solid argument for tight control and frequent blood glucose monitoring. If one is ill, or knows his or her sugars have been running over 240 mg/dl for some time, urine should be tested for the presence of ketones. When in doubt, one should test (several urine tests for ketones are available) and remember to keep the health care team informed.

Necrobiosis Lipoidica Diabeticorum

NFB Diabetes Action Network

Necrobiosis lipoidica diabeticorum (NLD), also known as diabetic dermopathy, is a condition in which reddish spots appear on the skin, generally in the front of the lower legs, though they can appear in the back of the legs, the feet, the thighs, the hands, and elsewhere. Little is known about the cause of NLD, but some without diabetes also develop the condition, and they generally come from families and groups with strong genetic predispositions toward diabetes.

The scaly, reddish-yellow patches of NLD have no known relationship to one's diabetes control or complications. They are neither signs of gangrene nor indications of incipient neuropathy. In fact, they don't appear to signal anything at all. If a doctor tells a patient that's what he or she has (and one should get a doctor's opinion), these patches can usually be treated with a skin-moisturizing ointment (lanolin, vaseline, etc.) and a resolution not to lose sleep over them.

PART FOUR: EMPLOYMENT ISSUES

Diabetes and the IWRP

NFB Diabetes Action Network

Blind diabetics constitute a significant percentage of those entering rehabilitation programs. They have their own special needs and capabilities. Review of the aspects of diabetes pertinent to the Individualized Written Rehabilitation Program (IWRP), which is prepared for all rehabilitation clients, can help clarify the process by which such goals are set.

There are a great many fictions and misconceptions about diabetes. Some are held by the client; others by the world at large. Many do not know that most blind diabetics can return to employment once they achieve independence. Spreading the message that with appropriate adaptive equipment and training individuals who are blind are fully capable of independent self-management, the rehabilitation professional can be the voice of truth.

Because most diabetics who experience vision loss do so as adults, acceptance of blindness can be a problem. Rehabilitation professionals should encourage use of nonsighted techniques rather than teaching those with partial vision (which may or may not, after all, even remain stable) to utilize more fully remaining vision. The individual who is taught with sleepshades, learning nonsighted techniques before they are necessary, is not only properly prepared for the eventuality of further sight loss but has also learned success without vision. He/she has learned confidence and is better able to cope.

The confidence issue leads into the next aspect. No functional adult enjoys dependency, and with the proper adaptive equipment and training, diabetes and blindness need not mean loss of independence. Blood glucose monitors with voice synthesis "speak" both test instructions and results. Insulin gauges and adjustable tactile insulin measurement devices enable nonsighted insulin-drawing and provide a high degree of accuracy. Talking bathroom scales, blood pressure monitors, and fever thermometers allow transplant recipients who are blind or dialysis patients to monitor their health without relying on sighted aids. This adaptive diabetes equipment is critical to rehabilitation goals and is just as important for independent daily living as are white canes and kitchen tools. Medicare reimburses for talking glucose meters and reagent test strips, if the client is an insulin-user. Other devices should be provided for the client. A state agency may require certification of need by a physician or diabetes educator.

Diabetes brings its own issues to the blindness rehabilitation field. Many diabetics will experience "fluctuating vision," a condition in which sight may change from functional to unusable, and back again, within days or hours. For these consumers who cannot count on vision to help draw insulin or measure blood glucose, nonsighted techniques and equipment are necessary. Diabetic retinopathy, the immediate cause of so much sight loss, often leads to deteriorating vision. An individual with retinopathy can experience a steady diminution in remaining visual acuity and needs to master nonsighted techniques. Diabetic neuropathy, nerve damage, can impair certain tactile skills, such as cooking or Braille use, requiring mastery of alternative skills and techniques.

It is accepted today that the advantages of modern diabetes care should be as accessible to blind people as to the sighted. Both ethics and the spirit of the Americans With Disabilities Act require it. Adaptive diabetes self-care skills need to be part of the IWRP package. Agencies need to have access to diabetes educators because many of the issues of diabetes are complex and specific. At the same time, rehabilitation professionals should remember many of their diabetic clients have already mastered independent self-management and need simply to translate those diabetes skills into their nonsighted equivalents.

Where some vision is present, the instructor needs to foster use of nonsighted techniques rather than teach reliance on a failing resource. Learning with sleepshades in a competently conducted program fosters acceptance of blindness, just as mastery of nonsighted techniques engenders self-reliance, and helps communicate that blindness is not synonymous with *inability*. With the appropriate adaptive equipment and training, blind diabetics are capable of real success.

Blind Diabetics at Work

NFB Diabetes Action Network

Although many employers are still reluctant to hire blind people, and especially blind diabetics, their fears prove groundless when examined in the light of reason. A diabetic who keeps his or her disease under good control is capable of nearly any job under nearly any working conditions. Once simple criteria are met, a blind diabetic is as capable as any other blind person of gainful employment and serious contribution to society.

The Americans With Disabilities Act of 1990 requires that employers "provide reasonable accommodations" for individuals with disabilities who are otherwise capable of performing their job duties. For diabetics, what are those reasonable accommodations?

Diabetes self-management is above all else a process of scheduling. To keep blood sugars in the safe range, minimizing short-term risks of insulin reaction and DKA and long-term risks of ramifications, individuals with diabetes need to test on schedule, take their medications on schedule, and eat on schedule. If involved in strenuous physical activity, they need to ensure that it is of a sufficiently consistent nature that the diabetic can make allowances for it in his/her medication schedule and meal plan. Diabetics can and do run the Boston Marathon; because they have prepared for the stress of the race, they test their blood sugars as they go, and they eat snacks as needed to stay in the safe range. Most workplace environments are nothing like the Boston Marathon, but the same principles apply:

1. Be prepared for the stresses and exertions of the job.
2. Test blood sugars regularly and frequently to be sure.

3. Eat consistently to keep blood glucose readings safe.

What should a potential employer do? Recognize that the diabetic employee is just as capable as any other, and also recognize this individual's need for snacks to keep blood sugars in the safe range. While other employees are having coffee or a cigarette, the diabetic employee will be ensuring his/her continued quality performance. It's no big deal, and it doesn't take a lot of time. What if the diabetic is blind? Once diabetes is under good control, there is absolutely no difference between the abilities of a blind diabetic and those of any other blind person. Provided the tools and training, blind individuals are fully capable of mainstream living and gainful employment.

So what should the rehabilitation professional do? After all, it's his or her job to get the client into mainstream living and gainful employment. The professional needs to make sure the appropriate tools for independent diabetes self-management are in the client's hands, along with the training in their use. The blind client may have received a lot of negativity about his/her capacities for employment, and rehabilitation professionals should be ready to bolster their clients' confidence in their own abilities. Encouragement and positive examples can work wonders.

The Use of Braille by Blind Diabetics

NFB Diabetes Action Network

Braille, the tactile alternative alphabet invented by Frenchman

Louis Braille in the 19th century, is the key to literacy for many blind people, in many different parts of the world. It can be adapted to almost any language, and to any alphabetic script. Many materials are published in Braille format, and an experienced Braille reader can be just as fast and competent as a sighted reader. However, Braille is not appropriate for some blind diabetics, although many others use it well.

Long-term diabetes can bring many complications, and one of the most insidious is neuropathy, gradual deterioration of the nervous system. Peripheral neuropathy can lead to pain or to increasing numbness in the extremities. Some folks can read Braille for a few minutes; then the pressure causes numbness, and they have to stop for a time. An individual with neuropathy may find the differences between Braille "letters" undetectable, or may not be able to sense their presence at all. For such a person "Grade Two Braille," the standard for most publications, is of no more use than is printed text.

Alternatives. For some people with neuropathy, "Jumbo" Braille may be detectable, although most Braille library materials are not published in this format. Others may be best served by an embossed-letter system such as the Fishburne Alphabet (Fishburne Enterprises, 140 East Stetson, Suite 319, Hemet, CA 92543; telephone (909) 765-9276 or Fax (909) 766-0843], which allows tactile labelling and object identification, although too unwieldy for text.

But there are a great many degrees of neuropathy. Once the condition appears, it may worsen, or it may improve with tighter control of blood sugars. Some people may be able to detect only the most extreme tactile variations, and for them "talking books" and synthesized speech computers and medical equipment are better choices for independence.

No situation is hopeless. Adaptive technology routinely helps achieve goals impossible a decade ago. Though Braille is important, it is after all only one of the available tools.

Health Insurance

NFB Diabetes Action Network

People with diabetes or any other chronic condition can have a difficult time obtaining health insurance coverage. Private insurers often either exclude diabetics entirely or place them in prohibitively expensive "high risk" categories. "Preexisting condition" exclusions may find the diabetic covered for everything but the costs of diabetes.

The best answer is to find an employer whose health insurance benefit package (or group insurance plan) does not exclude diabetes (and check the small print). Such a benefit may be worth more in the long run than a higher salary or more opportunities for advancement. Many federal and state positions offer such benefits. If one is checking out potential employers, it is essential to read the insurance fine print carefully, and when one finds a job with insurance that covers employees with diabetes, there should be no hurry to leave it.

If one is eligible for Medicare, it will supply some of the basic elements of insurance, but it may be necessary to consider limitations on the number of hours one may work or on the total amount which may be earned in a given period. Part-time employment may allow Medicare benefits to continue. Medicare beneficiaries should check with a Social Security office to determine applicable provisions.

All concerned should be aware the insurance industry is in a state of flux because new federal laws will alter traditional practices. Public Law #104-191 (HR 3103), the "Health Insurance Portability and Accountability Act," signed on August 21, 1996, limits insurers' rights to impose preexisting conditions waiting periods or to exclude individuals outright. This law, scheduled to be in force on July 1, 1997, is complex, and it will be some time before all implications are known. Diabetics should watch their insurance coverage closely and realize they may have new rights.

Scleral Shells

NFB Diabetes Action Network

In our culture in general and at work in particular, it is important to "look people in the eye." A person's blindness is no exception. People whose experience matches mine might benefit from the answer I found when, as a consequence of sight loss, my eyeballs shrank, making it impossible for me to open my eyelids.

Scleral shells are prostheses that look and fit like natural, living eyes. Today's custom-fitted prostheses, fitting over the wearer's eyeballs, can often fool sighted persons. Prices for custom-made scleral shells run from approximately $900 to $1,700 apiece, and the shells can last for decades.

Because people in social situations are more at ease talking with someone whose eyes are open, head up, looking directly at the speaker, I find the shells helpful. Scleral shells make the eye appear almost normal, a benefit to anyone who recognizes the importance of direct eye contact in work or social situations, where it has come to symbolize paying attention. Thus, they help foster positive attitudes both for and about blind people.

Not everyone can use scleral shells. Some individuals are irritated by the prostheses; others' shape requirements cannot be accommodated. Unfortunately, some insurance companies will not reimburse the cost of scleral shells, considering them cosmetic.

Every client has individual needs and preferences. A good oculist offers several types of ocular prostheses. For those who have lost an entire eye (globe), there is a prosthesis that fits comfortably to the shape of the socket. For those whose globes are intact, there is the scleral shell prosthesis, a thin cover that fits entirely over the patient's own globe. In addition to presenting the appearance of a natural eye, the scleral shell helps allow the eyelids to open.

To present the appearance of living tissue, the actual coloring of the prosthetic eye is done with the greatest care. The goal is to duplicate the appearance of healthy eyes. "Veins" (fine fibers of red cotton thread) are painstakingly placed on the surface of the prosthesis in such a manner as to duplicate living veining patterns. The entire painting process usually takes 3 or 4 hours.

Many blind diabetics have obtained scleral shell prostheses. They indicate their shells make a definite difference in their lives. They feel better about their appearance, and find that they can more easily converse with others, knowing that their eyes appear basically normal.

PART FIVE: DEALING WITH THE EMOTIONAL ASPECTS OF DIABETES

The Emotional Side

NFB Diabetes Action Network

Diabetes is incurable. It imposes restrictions on one's lifestyle, causes a long list of complications, and can shorten life. To survive, one must diligently follow a prescribed routine one did not choose. On top of all that, blindness may come as an additional complication. Diabetes is not subtle, and the emotional aspects need to be considered.

"Don't it always seem to go that you don't know what you got 'til it's gone," sang Joni Mitchell so many years ago. Diabetes can certainly make that song ring true, for every diabetic lives with the threat of complications. The Diabetes Control and Complications Trial proved that the best possible control reduces that threat, but a significant number do their best and still suffer major ramifications. Even with what we know today, there is always that dreadful uncertainty.

Understandably, most diabetes education materials focus on the physical aspects of the disease. This is appropriate. But the common emotional ramifications of diabetes need to be taken into account. An individual's emotional state may determine whether one prevails or is felled by circumstances.

Anger. "Why ME?" is an altogether common reaction to a serious health crisis like diabetes. We don't know what causes it. Although we can manipulate statistics and use them to make predictions, we can't tell why a given individual gets diabetes or any of its ramifications. And tight control helps, but it is no panacea.

People used to believe that disability was the result of defective character. If you developed a disease, you had brought it on yourself; you were a "failure." We know better, but too many of us still judge ourselves harshly, blaming ourselves for "being weak." Diabetes is not a sign of weakness.

Some may ask, "What did I do to deserve this?" People do not develop diabetes or its ramifications because they "deserve them." We don't know why one person gets it and another does not. We have to do the best we can. Diabetes can be nasty and unpleasant, but it is not "diabolical." It is not a punishment.

Denial. Some react with the declaration, "It will never happen to ME!" Social workers and psychologists are very familiar with the problem of denial, the conviction that in spite of the facts, the rules do not apply in this particular case. The ramifications of diabetes do not appear immediately, but the more time spent with high blood sugars, the greater the likelihood of future eye, kidney, and nervous system complications. The diabetic who seeks to prove that he or she is "exempt" and "gets away with it," short-term, is only increasing the likelihood of down-the-line problems. The literature is full of stories concerning diabetics who were noncompliant in their youth but saw the error of their ways about the time their vision began to fail. Denial is a common problem and one that should be addressed right along with the need for conscientious self-management.

People familiar with blindness have heard the newly blind protest, "No! I'm not BLIND!" Sight loss brings its own denial. There are people who won't use their canes, or learn Braille, or even stop driving because they cannot admit they are going blind. Some delay learning adaptive skills with, "It's only temporary; I'm sure my sight will come back!"

Fear. "What am I going to do? I won't be able to. . . ." Whereas some people deny they'll ever be affected, others swing to the opposite extreme. They pay close attention, read the reports, and work diligently, but for them there are demons under the bed, and figuratively "every bullet has their name on it." Too many are convinced that a diagnosis of diabetes or the need to start injecting insulin, or blindness, kidney failure, or any of the other possible complications, means the cessation of life as they know it. It doesn't. With proper adaptive equipment and training, individuals who are blind, losing vision, even those coping with multiple ramifications, such as blindness, amputation, and kidney failure, can maintain or recover independence, and remain (or become!) fully productive participants in mainstream society. Fear, or the use of fear to encourage diligent compliance, is counterproductive, as we shall see below.

Burnout. Some complain, "I'm tired of it!" Diabetes self-management is a discipline, 7 days a week, from now until doomsday. There are no reprieves, no opportunity to take breaks, and short of a pancreas transplant, there is yet no cure. There is only the routine, day after day after day.

Some people thrive. Presented with the findings of the DCCT, and the need for multiple monitoring and injections, one young man said, "Of course I will! I want to stay healthy as long as possible!" He was and is ready. Others find the prospects daunting.

A lifetime of dietary restrictions, regular exercise, blood glucose testing, and multiple injections or oral medications can become wearing, especially after a number of years with the condition. Some get tired of it; others come to hate "doing it because they must." Still others stop believing their own welfare is "worth the fuss." This is "burnout," psychological rebellion against one's duties.

When burnout leads to non-compliance, it is a recipe for trouble. Why do some "burn out" and not others? The answer is ***attitude***. Those who thrive, who make the best of a less than perfect situation, are like savvy poker players who, dealt a doubtful hand, play it for all it's worth. Often these outperform the ones holding the aces! They learn that it's not the cards you're dealt; it's how you play the game.

"Positive attitude" can mean many different things, but here it means a wholehearted belief in one's own capacities and determination to overcome all obstacles, regardless of how long it takes. If people don't believe in themselves, even the small hills can look impassable.

Loss of Independence

Then there are the familiar complaints: "How can I face my friends? How can I get anything done? I can't DO anything!" Too many people respond to disability or other trauma with the "wounded animal response"--flight to solitude, to "lick one's wounds." Up to a point, this is part of the grieving process, the mourning for what must be let go. When it passes, rehabilitation can begin.

But some "get stuck" there. Some independent, self-reliant people, high achievers, can be more traumatized by their own "incapacity" than by their actual physical loss. The belief revealed by the attitude, "I have lost something and am now less than I was" discourages action. This feeling can occur with most any incapacity, but is not uncommon in cases of sight loss.

An adult with type I diabetes, for example, may have been self-managing for 15 years or more, before retinopathy put an end to a sight-based lifestyle. Some, with a positive attitude, good instruction, and proper adaptive equipment, make a smooth transition. Others wilt.

So many times it is again a question of attitude. An individual is accustomed to being in charge, to caring for self and others, and to being a productive member of society. In his or her mind, loss of sight means the end of the capacity to continue doing so. Feeling diminished, feeling ashamed, the individual withdraws from society and stays "out of circulation." Belief in his/her incapacity has become a self-fulfilling prophecy.

These people are not lazy. They are not "slackers," taking a long vacation from responsibility. They are in emotional agony, grieving for losses they don't know how to replace. These people need to be shown their options. They need to hear of (or from) others like themselves, who have looked the demon of self-doubt in the eye and moved forward anyway. They need support groups and rehabilitation professionals who will respect their self-doubts and then show them how to overcome them. Some might declare, "You can't teach attitude!" What you can do, however, is show such people their options and then get out of the way.

The Cure

Nothing about diabetes, or any other disability, diminishes a person's humanity. Loss of sight, a limb, or mobility and independence does not make one "incomplete." There are no "partial people" out there; we all have our humanity intact.

But it hurts to have to give something up. We are not oxen, facing our traumas with placid equanimity. Fear and pain are perfectly logical responses. Some will pass smoothly through the stages of grief and be ready to learn the necessary adaptive skills. Most will need the support of their fellows and the positive examples of their predecessors, and will need to have their feelings validated. Passing this hurdle, they are ready for, and fully capable of, independent self-management and full participation in the mainstream.

The presence of emotional issues is not a sign of weakness but of humanity. Any holistic approach to health takes a person's mental/emotional state into account, right along with specific physical ramifications. We are individuals, and we each heal in our own way. [*Editor's Note: One reviewer found helpful "Diabetes: Caring for Your Emotions as well as Your Health" by Jerry Edelwich, MSW and Archie Brodsky (Addison-Wesley, Reading, MA).*]

We close this work with two testimonials to the power of attitudinal change and knowledge to effect happy and productive lives. In these narratives, the reader will find the spirit, determination, and good sense all rehabilitation professionals look for or attempt to build in their clients.

How I Went Blind...and Then What

Ed Bryant

Since so many lose sight from diabetes, perhaps a review of my own experiences might be beneficial. Diabetes is a sneaky disease. It usually takes 15 to 20 years before chronic complications are noticeable, and there are many complications that can stem from the disease. Blindness is one, so I'd like to share my eye experiences and some observations about blindness.

Thirty-six years ago, I was diagnosed with early onset diabetes. After the initial shock of discovering I had diabetes, and after learning how to give myself insulin injections, my lifestyle returned to one of a very busy and active teenager. The only differences were that I had to give myself one shot a day and watch my diet. Eating a lot of sweets could cause problems.

At first, I did not adhere to good diabetes practices. I was not good at watching what I ate and drank. I did what my peers did, and I felt just fine. I was not worried about my diabetes. Then, after I'd had the disease almost 16 years, I began to notice some blurred vision. It was like looking through a smoky haze.

At first, I didn't pay much attention. In St. Louis, where I was administrative manager for a corporation specializing in child photography, my job required a lot of paperwork. I assumed I needed to see an eye doctor and get glasses. But I didn't get glasses, and my vision deteriorated with time. Finally, admitting I'd been foolish, I saw an ophthalmologist, who diagnosed proliferative diabetic retinopathy. I had no functional vision in one eye, and the prognosis for the other was not good. The doctor recommended I see a diabetes specialist and get my disease under good control. Then, if possible, he could give me laser treatments.

I immediately saw a physician who specialized in diabetes. I worked to regulate my disease far more closely. In time, with my diabetes under good control, the vision in my one functional eye became substantially better. I was elated. I could see well enough again to do almost anything. Working as a photographer, I had driven in every state in America, and of course, I thought driving a car was essential to everyone's lifestyle. Now I could even drive my little blue sports car again!

When I revisited my ophthalmologist, we decided to try vitrectomy surgery in my bad eye. With luck, it would restore some of my vision. The surgery failed, as did a second vitrectomy on the same eye several months later. I knew that by law I was legally blind, but I didn't consider myself blind since I had so little trouble getting around and doing what I wanted to do.

During the daytime, my only troubles came while facing direct sunlight. My difficulties were at night. Unless an area was well lit, I had trouble seeing where I was going. Late one evening, I started walking home. The area was well lit, but as I progressed, there were fewer and fewer street lights. Soon I could barely see my path. At a wide point in the sidewalk, landscapers had planted a preposterously huge tree, right in my way! I was walking at a pretty good clip--and I ran into the tree. After my very "close encounter," and a few frank words with that tree, I walked the rest of the way home. As I look back, I can only laugh. If I'd had more wisdom, I'd have been using a long white cane. Then I could have avoided both possible injury and the tree.

Several years later, my employment was phased out. I found myself out of work. I moved to Columbia, MO, home of the University of Missouri. I would work out my future from there. I had been offered upper-middle management positions with several different companies, with very lucrative salaries.

As soon as I told prospective employers I was legally blind, or that I had "a severe eye problem", their offers no longer stood. The jobs were either "no longer available" or offered to me at wages less than half their original offer. It didn't matter that I could do the work proficiently. My experience in business administration and public relations didn't count. When employers heard the words "blind" or "legally blind," they immediately assumed I was incapable of doing the job.

Out one night in Columbia, a friend accidentally poked me in my good eye. I felt excruciating pain. My ophthalmologist recommended a retina surgeon in Memphis, TN. The specialist told me the eye was in bad shape but vitrectomy surgery might help. Once again, I underwent surgery. However, it only allowed me to see in a very limited way.

In the following few months, I lost my vision completely. I was totally blind. I lived in an apartment, and I really had no way to get around. After managing my personal business matters, after being independent for years, I found it very difficult to let another person become involved. My parents offered to build an extra room onto their home so I could live there. Although the offer was loving and gracious, I would never consider such a thing. I'd always been an independent person, and if I'd moved into my parents' home on a rural route, I would have been more or less trapped, since there was no bus service in the area, and the cost of a taxi to and from the country was very expensive. I couldn't expect my parents to provide my transportation everywhere. They had their own life!

I was a very active person, used to travelling. I decided to keep my apartment. I had no wish or reason to become dependent on others. I knew I was perfectly capable of doing the things I'd always done! My biggest problem was not being able to draw up my own insulin. My mother drew up a 7-day supply, every week for 3 or 4 years, until I learned of devices that allowed blind persons to draw their own insulin accurately. Such a device allowed me to manage my own disease independently.

My blindness made me angry and frustrated. Like so many newly blind people, I felt trapped and limited in what I could do. The fact was--I was blind. But it seemed unreasonable to give up and abandon independence simply because I couldn't see. I began to realize that in actuality I wasn't limited. I could function very well in my apartment. I knew where everything was; with a little ingenuity, I discovered I could cook and do anything in the kitchen. Every day I discovered alternative techniques that allowed me to do things just as well as I did when I was sighted. I was learning how to help myself.

I telephoned Missouri's Bureau for the Blind and asked for a white cane and someone to show me how to use it. After waiting 2 or 3 weeks, I got angry. How could I be independent if I had to stay in my apartment? So one day, I took a hatchet and a kitchen broom and went outside, using my broom as a cane. I headed for a spot where I knew a little tree was located, and I chopped off a long branch. Returning to my apartment with my prize, I chopped and whittled until the branch developed into what I called a cane. I didn't know anything about cane dimensions, but I figured it should be about as tall as I was. I ended up with a makeshift cane about 6 feet long.

I went for short walks. I chuckle about it now, but I was probably a danger to society with my tree branch cane. I was certainly a danger to myself. The end of the cane kept getting stuck in the ground, and I came close to rupturing my midsection on many occasions. Even though my cane was home-made, it helped me get around the apartment complex and many nearby roads. I had all the confidence in the world.

At last, the man from the Bureau for the Blind arrived, bringing me a better cane. After he left, I went for a walk. The top of my new cane reached somewhere between my navel and breastbone. I had to bend over as I walked with it, and it was obviously too short, but I could do a lot better with it than with my tree branch. I knew where the city bus stopped, so I took a bus downtown and spent the afternoon exploring.

I never had any formal mobility lessons, but I trained myself without great difficulty. I finally moved to the downtown area, primarily because there were sidewalks. I lived in a high-rise apartment close to the University. There were many social activities, and something was always happening. There was plenty out there for a guy like me.

At some point, I found out about the National Federation of the Blind (NFB). After attending a few meetings, I was more impressed with it than with any organization in which I had ever been involved. It was a united body of blind people, doing everything possible to serve all blind people, without regard to the cause of their blindness. Federation philosophy ran parallel to my own observations made since I had gone blind, that much of the general public simply does not understand blindness. Many friends, neighbors, and family simply pity a blind person, thinking he/she is not capable of doing very much. Along with the pity and sympathy comes a great deal of discrimination due to society's many myths and misconceptions about blind people. The situation is improving, but we in the NFB still need to spread the word.

The key word is *education*. We Federationists are aware that, with proper training and use of alternative techniques, we can do just about anything we desire. The NFB knows that society's perception of "inabilities" can mislead blind people. If all they hear is how they're "helpless" or how "they can't", they may become convinced and think themselves into helplessness. Such holds true for the blind diabetic, told incorrectly by so many that he/she cannot draw insulin, test blood glucose, or perform the other tasks of diabetes self-management.

"Limitations," for most blind persons, are self-imposed. The NFB strives to enlighten society about the capabilities of blind people, while it strives to improve the way many blind people think about themselves. We encourage them to think "I can" rather than "I can't". We are a self-help and advocacy organization. We show blind people they are not alone, and that, whatever their situation, they have options. Our members are living proof that blindness is not synonymous with inability.

My Transformation

Betty Walker

I was born in 1953 in Dover Plains, NY. Despite being diagnosed with diabetes at age 5, my childhood was more or less "normal." I graduated from high school in 1971 and earned an A.A.S. degree in nursery education from Duchess Community College in Poughkeepsie, NY. My problems began at that time.

Glaucoma and diabetic retinopathy took my sight before the end of 1974. In January of 1978, I was confronted with renal failure as well. After coping with losing my sight, which I did by daily thanking God for each day, I felt this new development was just another of life's hurdles that I had to jump over. If I could not jump, I would climb, no matter how slowly.

When I went on hemodialysis, most of the time I felt very ill. I was so nauseated that I could not eat. My social life was nonexistent, and I no longer enjoyed any hobbies. I was so tired that most of the time between dialysis sessions I spent in bed. Life went on like that for about 6½ months. When I decided to have a kidney transplant, I figured I had nothing to lose. Dialysis was always there to fall back on.

On July 13, 1978, I was "born again." My mother, Fran Bator, gave me life when I was born and gave it to me again when she became my kidney donor. The transplant was done at Yale-New Haven Hospital. It should be called a "transformation" because that is what it was for me.

I could hardly believe it, but the day after the transplant, I wanted to eat! I was told that I had to wait 1 more day. Given Jello and ginger ale the next day, I told the doctors I wanted "real" food. The following day, request granted, I ate like a horse, devouring every bit of food on my tray. I felt like running or doing something to release my energy. My hematocrit rose from 12 to 40. All of my blood chemistries were now normal. The only problem was with my blood sugar, which had risen because of the steroid I was prescribed as postoperative medication.

The most frustrating thing for me was that I could not take a shower or a bath until my stitches were removed. Wouldn't you know it--they left them in for 16 days! As soon as the doctor removed the stitches and was out the door, I was in the shower.

Since I became blind, I have had this philosophy: I never say something CAN'T be done unless first I try it and know that I can't do it. So far, the only thing I've found I can't do is drive a car.

I lead a fairly active life since my transplant. My favorite leisure activity is horseback riding. Yes, it can be done by a person who is totally blind. I also enjoy swimming, hiking, sailing, ice-skating, arts and crafts, cooking, baking, and writing poetry.

I have now had my kidney transplant for 18½ years. I have had no major problems in those years, and my blood chemistries continue right in the middle of the normal range. I continue to do all of the things that I enjoy, and I work actively in the National Federation of the Blind.

APPENDIX: LIST OF RESOURCES

Information

The American Association of Diabetes Educators

The American Association of Diabetes Educators (AADE) maintains a list of Certified Diabetes Educators in different parts of the country. To find a diabetes educator near you, call (800) 832-6874.

American Council of the Blind
1155 - 15th Street N.W., Suite 720
Washington, DC 20005
(202) 467-5081
(800) 424-8666
Fax (202) 467-5085
E-mail acb@acb.org

The American Council of the Blind (ACB), founded in 1961, is a nonprofit organization committed to advancing social, economic, and educational opportunities for blind and visually impaired Americans. Council members are blind, visually impaired, and fully sighted individuals who come from all walks of life but share a common concern: the dignity and well-being of individuals who are blind.

ACB strives, through a variety of programs and services, to enable individuals who are blind to live and work independently, to become active in their communities, and to become participants in the democratic process. The Council has influenced change in such areas and issues as: education, transportation, employment, travel and recreation, rehabilitation, civil rights, and Social Security.

To strengthen advocacy efforts, the Council often works in coalition with other national disability groups. ACB has chapters in every state/region in the United States, and 22 special interest affiliated organizations which focus on the unique concerns of various professions and special populations, such as students who are blind, lawyers, teachers, parents, secretaries, business enterprises, etc. Like the national organization and state/regional affiliates, these special interest organizations offer their own newsletters, special projects, and annual meetings.

The Council issues and distributes free of charge a monthly magazine called the ***Braille Forum***. This is available in Braille, large print, recorded cassette, and computer disc. For access to the ***Braille Forum*** and other ACB materials, visit our web site at http://www.acb.org on the internet. In addition, a monthly half-hour radio program is taped and distributed to radio reading stations for individuals who are blind and print handicapped throughout the United States.

The American Council of the Blind is dedicated to furthering the education of persons who are blind or severely visually impaired. Annual scholarships in excess of $50,000 are awarded to post-secondary students entering college, technical and business schools, and those working on graduate degrees. The awardees are sponsored to travel to the annual national convention. Further information can be obtained from the national office by telephone or E-mail at hfults@erols.com with applications being post-marked by March 1st.

The annual national convention of ACB provides a week-long opportunity for people to hear and see the latest in adaptive aids, information and medical treatments that can assist individuals who are blind or severely visually impaired live more independent and productive lives. During this week, a blindness and diabetes seminar is held for attendees. Cassette tapes of the seminar can be purchased by contacting the Washington, DC office. The convention as well as leadership training seminars help educate individuals who are blind as well as sighted individuals about the abilities and positive roles that they can bring to their job and community.

ACB's toll-free telephone service (800) 424-8666 provides information about jobs as well as updated information on legislative issues of concern to individuals who are blind or severely visually impaired. ACB's web site http://www.acb.org also carries the "Washington Connection" and copies of many resource lists provided by ACB.

American Diabetes Association, Inc.
1600 Duke Street
Alexandria, VA 22314
(800) 232-3472

The Carroll Center
770 Centre Street
Newton, MA 02158
(617) 969-6200
(800) 852-3131
Fax (617) 969-6204
E-mail carroll@.TIAC.NET

Margaret Cleary of the Carroll Center has shared two excellent publications during the preparation of this monograph. The first is *Adaptive Education Resources*, excerpted from Ms. Cleary's *Diabetes and Visual Impairment: An Educator's Resource Guide*. The second is titled, *Guidelines for the Practice of Adaptive Diabetes Education for Visually Impaired Persons* (ADEVIP), containing recommendations generated by a working group of the American Association of Diabetes Educators.

Colorado Center for the Blind
1830 South Acoma Street
Denver, CO 80223-3606
(800) 401-4632 or (303) 778-1130

Descriptive Video Service (DVS)
DVS Home Video
1000 Westgate Drive
St. Paul, MN 55114
(317) 579-0439

DVS is a service by which classic and contemporary VHS videocassettes are modified to include a narration track. In no way interfering with the movie's sound or action, the narration allows blind individuals to follow the action. To watch and listen to DVS-modified cassettes, no special hardware is required; one needs only a conventional television and VHS player. These videos are priced the same as the unmodified releases. Incidentally, all DVS videocassettes also carry closed captioning for the deaf.

DVS-modified programs are also available on television in some Public Broadcasting Service (PBS) programs and some cable programming on the TCM (Turner Classic Movies) channel. To receive this narration, the consumer needs a stereo TV or stereo VCR equipped with the Second Audio Program (SAP) feature. DVS also offers a free quarterly catalog in large print or Braille.

Lions International
International Activities and Program Development Division
300 22nd Street
Oak Brook, IL 60521-8842
(630) 571-5466

Lions Clubs are known across the world for their work with programs for individuals who are blind and sight conservation. They also conduct extensive programs on diabetes awareness.

Medic Alert Foundation
2323 Colorado Avenue
Turlock, CA 95381
(800) 344-3226

Medic Alert offers "body-worn medical ID" (bracelets and necklaces) that both inform emergency personnel of the wearer's pre-existing medical conditions, and provide a 24-hour telephone "hot line" to a database with more in-depth medical information.

The National Diabetes Information Clearinghouse (NDIC)
1 Information Way
Bethesda, MD 20892-3560
(301) 654-3327

Part of the National Institute of Diabetes and Digestive and Kidney Diseases, an agency of the U.S. government, the NDIC publishes a number of informational pamphlets about aspects of diabetes, most free of charge in single copy, also the newsletter *Diabetes Dateline*.

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(410) 659-9314
Fax (410) 685-5653
E-mail nfb@access.digex.net

The National Federation of the Blind (NFB), founded in 1940, is a support and advocacy organization of blind people. It is dedicated to breaking the barriers between blind folks and full participation in the mainstream. The Federation's primary national publication, the monthly *Braille Monitor*, deals with all aspects of blindness and is offered in print, Braille, and audiocassette for the blind, free upon request. The NFB is also the only national organization of the blind with a publication about diabetes and blindness; *Voice of the Diabetic*. The NFB's many divisions focus on specific aspects of blindness, and its Aids, Appliances and Materials Center functions as a low-cost outlet for equipment and information for the blind (hours of operation: 12:30 to 5 p.m. weekdays Eastern Time). To learn more about the NFB and its divisions, or to obtain a copy of the Materials Center's free catalogs (in large print or Braille), contact them at the address above, or find them and many of their publications on the World Wide Web at: http://www.nfb.org or on their "NFBNET" BBS: (612) 696-1975.

The *Braille Monitor* is now available by E-mail subscription, in which it is shipped to your E-mail address once a month. To receive it in this way (you can also download it from the NFB web site) send an E-mail message from the address where you wish to receive your monthly mailings to: listserv@braille.org. In the message body type: "subscribe brl-monitor first name last name" (insert your own first and last names). For E-mail information about this service, contact: postmaster@braille.org. To communicate with the NFB by E-mail, use the nfb@access.digex.net address.

NFB Scholarship Program. Each year, NFB awards approximately $88,000 in merit-based scholarships. Competition is open to any legally blind individual; NFB membership is not required. Most awards for postsecondary education are unrestricted. Scholarships are awarded at the NFB National Convention in July; winners also receive all-expenses-paid trips to the convention. The scholarship application closing date is March 31, for any given year. For information, contact the NFB Scholarship Committee at the address above.

International Braille and Technology Center for the Blind. The NFB maintains, as a public service, examples of every adaptive computer with speech or Braille output. The IBTC, the world's largest computerized technology demonstration and evaluation center for the blind, offers expert advice on choice of computer hardware and programs, and is open to both agencies and individuals. No products are sold at the Technology Center, so equipment is judged impartially. For information, contact Richard Ring, IBTC Director at the NFB address above; telephone (410) 659-9314.

Exchange Lists for Meal Planning. The 1995 edition of the publication, *Exchange Lists for Meal Planning* is now available in Braille (74 pages) and on audiocassette. This update, the result of joint efforts of the American Diabetes Association and the American Dietetic Association, reflects the new emphasis on total carbohydrate intake, rather than restricting specific sugar types. Users should find its new orientation simpler, and its meal plans vastly more flexible. To order, contact: NFB Materials Center, at the above address. Cost: Braille $10, cassette $2.

Job Opportunities for the Blind (J.O.B.), Lorraine Rovig, Director: (800) 638-7518: J.O.B. is a joint project of the U.S. Department of Labor and the NFB. The program offers free services to U.S. residents who are blind and looking for work in the U.S. Services include nationwide reference and job referral, a job hunter's magazine on cassette (the *JOB Recorded Bulletin*, published six times a year), recorded job information literature, print materials for employer education, local and national career-planning seminars, consultation on low vision aids and appliances, and introductions to blind peers employed in jobs of interest to the job seeker. For a free sample JOB packet, or to learn more about Job Opportunities for the Blind, telephone weekdays, 12:30 to 5:00 pm Eastern Time.

The Diabetes Action Network of the NFB. The Diabetes Action Network is a national support and information network for all diabetics, both blind and sighted. The Network maintains a number of Support Committees, whose members are ready to offer experience-based personal advice to individuals with questions about kidney failure, heart disease, stroke, amputation, male impotence, insulin pump use, or legislation affecting diabetes and blindness. The Network publishes both *Voice of the Diabetic* (see below) and the *Resource Guide to Aids and Appliances*, and offers the pamphlet, *Diabetes, Complications, Options*.

Resource Guide to Aids and Appliances. Every 2 years, the Diabetes Action Network compiles its list of companies and individuals who offer products and/or information for diabetics, especially those who are blind or losing vision, to help them self-manage their diabetes. The *Resource Guide* features six subject categories: General and Miscellaneous, Automatic Insulin Injection Systems, Blood Glucose Monitoring Systems, Syringe Magnifiers, Insulin Pumps, and Large Distributors of Diabetes Equipment and Supplies.

The *Resource Guide* costs $2 per copy and is available in Braille (30 pages), large print (14 pages), and audiocassette versions. Checks should be made payable to NFB (Visa, MasterCard, or Discover also accepted). Order from: NFB Materials Center (address above). One can also access the *Resource Guide* on the World Wide Web at: http://www.nfb.org, following the link for "diabetes" from the NFB home page.

The National Library Service
for the Blind and Physically Handicapped
Library of Congress
Washington, DC 20542
(800) 424-8567

The National Library Service (NLS) is part of the Library of Congress, with the specific mission of ensuring access to published materials for individuals unable to read print. Through its network of Regional Libraries for the Blind and Physically Handicapped, the NLS circulates materials in Braille, on "talking book record" (an old format now being phased out), and on 15/16 ips audiocassette. The NLS also supervises the free distribution of special tape players, available to any individual certified legally blind or otherwise unable to read print. In its collections, the NLS includes several titles on aspects of diabetes. To learn more about the NLS, its network of Regional Libraries, its collections, or its tape player lending program, call the national information number (800) 424-8567. You can also access the NLS, or search for a specific title, on the World Wide Web at: http://lcweb.loc.gov/nls

Vision Foundation, Inc.
818 Mt. Auburn Street
Watertown, MA 02172
(617) 926-4232

The Vision Foundation is a self-help group for adults coping with sight loss. It offers information and resources relevant to all types of blindness. Its *Vision Resource List* is available in large print and audiocassette, free of charge.

Low-Sugar Products

The EQUAL Cookbook
EQUAL Consumer Affairs
Box 830
Deerfield, IL 60015
(800) 323-5316

Available free, on cassette, in large print, or Braille, this cookbook contains recipes assembled with NutraSweet instead of sugar. All recipes include diabetic food exchanges.

Sugar Free Marketplace
6710 N. University Drive
Tamarac, FL 33321
(800) 726-6191

Sells foods, drinks, and desserts for persons with diabetes and offers a free catalog in standard print or on audiocassette.

Diabetes Publications

Diabetes Forecast
American Diabetes Association, Inc.
1600 Duke Street
Alexandria, VA 22314
(800) 232-3472 or (703) 549-1500

A national consumer diabetes magazine, published monthly. Cost: $24 per year. The magazine is not available in adaptive format. You can access *Diabetes Forecast* on the World Wide Web at: http://www.diabetes.org/Publications/magazine/forecast/default.htm

Diabetes Self-Management
P.O. Box 51125
Boulder, CO 80323-1125

A national consumer diabetes magazine, published bi-monthly. Cost: $18 per year. Not available in adaptive format.

THE MONITOR
LifeScan, Inc.
P.O. Box 60868
Palo Alto, CA 94306-0868

A healthy lifestyle journal for people with diabetes, published quarterly and free of charge.

Voice of the Diabetic
The Diabetes Action Network
of the National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
Editorial Office Phone (573) 875-8911
Editorial Office Fax (573) 875-8902

Voice of the Diabetic is a national free quarterly consumer news magazine dealing with all aspects of diabetes. It is a positive, upbeat publication emphasizing good diabetes control, proper diet, self-reliance, and independence. Along with personal stories and the latest diabetes news, the *Voice* features a "resource column" of aids and appliances, reviews of talking blood glucose monitors and adaptive insulin measurement devices, a "Recipe Corner," and a column of medical questions answered by an insulin-dependent physician. The *Voice*, the largest publication in the diabetes and blindness field, and the largest diabetes publication available in adaptive format (audiocassette), is available free upon request. Diabetes is a family disease, and many blind readers request copies in print as well, so family members can educate themselves about the condition. Contributors are always welcomed, and multiple copies, both standard print, and cassette are supplied free upon request. You can also access the *Voice* on the World Wide Web at http://www.nfb.org/voice.htm

Products for the Blind

Carolyn's Catalog
1415 57th Avenue
West Bradenton, FL 34207
(800) 648-2266

Adaptive equipment distributor; free catalog in standard print.

Independent Living Aids, Inc.
27 East Mall
Plainview, NY 11803-4404
(800) 537-2118

Adaptive equipment distributor; free catalog on cassette or in standard print.

The Lighthouse, Inc.
36-20 Northern Boulevard
Long Island City, NY 11101
(800) 829-0500

Adaptive equipment distributor; free catalog in large print, Braille, computer disk, or cassette.

L S & S Group
P.O. Box 673
Northbrook, IL 60065
(800) 468-4789

Adaptive equipment distributor; free catalog in standard print.

Maxi Aids
42 Executive Boulevard, Box 3209
Farmingdale, NY 11735
(800) 522-6294

Adaptive equipment distributor; free large print catalog; cassette costs $2.50, applicable toward first order.

Diabetes Equipment and Supplies

[These distributors offer free catalogs in standard print.]

Diabetes Self-Care
3601 Thirlane Road, NW, Suite 4
Roanoke, VA 24019
(800) 258-9559

Offers a full line of diabetes equipment and pharmaceuticals, training programs, and direct billing of insurance claims.

Diabetes Supplies
275 Curry Hollow Road
Pittsburgh, PA 15236
(800) 622-5587

Diabetes equipment and supplies; $4.00 handling charge. No third party insurance carriers accepted; customer must file for reimbursement.

St. Louis Medical Supply
10821 Manchester Road
Kirkwood, MO 63122
(800) 950-6020

Diabetes equipment and supplies; $4.25 handling charge. Medicare assignment accepted; sales tax on all Missouri orders except insulin.

Health-Mor Personal Care Corp.
P.O. Box 311
Bradley, IL 60915
(800) 991-4464

AdvantaJet Needle-Free Injection System: Automatic jet-stream injection system; tactile detentes for each unit drawn. Price includes training, 24-hour help line, free loaner. Suggested retail price: $795.

Medi-Ject
1840 Berkshire Lane
Minneapolis, MN 55441
(800) 328-3074

Medi-Jector (MJ6): Needle-free injector, measures in 0.5-unit increments; tactile and visual cues. With practice, should be suitable for independent use by blind diabetics. Two versions: adult and pediatric. Cost: $595.

Vitajet Corporation
27075 Cabot Road, #102
Laguna Hills, CA 92653
(714) 582-0713

Vitajet: Needle-free insulin injector; delivers from 2 to 50 units; adjustable jet pressure; some capacity for mixing insulins; raised dosage scale and some tactile cues facilitate low vision administration. Three year warranty. Cost: $695.

Insulin Syringe Magnifiers

Apothecary Products, Inc.
11531 Rupp Drive
Burnsville, MN 55337-1295
(612) 890-1940

The Ezy-Dose Syringe Magnifier.

Becton Dickinson Consumer Products
One Becton Drive
Franklin Lakes, NJ 07417-1883
(800) 237-4554

The Magniguide.

Cemco
20235 Olinda Trail
Marine, MN 55047
(612) 433-3374

The Cemco Syringe Magnifier.

Palco Labs, Inc.
8030 Soquel Avenue, #104
Santa Cruz, CA 95062
(800) 346-4488

The Insul-eze 6000.

Diabetes and Blindness Information on the Internet

Listservs

An E-mail list is a "club" of sorts; an association whose members "post" (E-mail) their messages "to the list" (so every member receives a copy) or to a specific individual. Most lists are topical, organized around one or more specific issues. Membership in the following lists is without charge.

BLINDFAM: "Everyday life experiences of blind persons, family and friends." To subscribe, send E-mail message to: listserv@sjuvm.stjohns.edu and in the message body, type: "subscribe blindfam your name"
The list's E-mail address is: BLINDFAM@SJUVM.STJOHNS.EDU

BLINDJOB: "Employment of blind persons."
To subscribe: send E-mail message to: listserv@sjuvm.stjohns.edu and in the message body, type: "subscribe blindjob your first name last name"
The list's E-mail address is: BLINDJOB@SJUVM.STJOHNS.EDU

DIABETES: "General discussions of diabetes issues."
To subscribe: send E-mail message to majordomo@world.std.com and in the message body, type: "subscribe diabetes"
This list's E-mail address is: DIABETES@WORLD.STD.COM

DIABETIC: General discussions of diabetes issues.
To subscribe: send E-mail to listserv@lehigh.edu and in the message body, type "subscribe diabetic your name"
This list's E-mail address is: DIABETIC@LEHIGH.EDU

Sites on the World Wide Web

[The sponsor identifications in parentheses below each WWW address are not part of the addresses.]

http://www.blazie.com
(Blazie Engineering, maker of Braille'n Speak)

http://www.beyondsight.com
(Beyond Sight, dealer in adaptive equipment for people who are blind)

http://www.diabetes.ca
(Canadian Diabetes Assn.)

http://www.tiac.net/users/carrollb
(Carroll Center for the Blind)

http://www.cdc.gov/nccdphp/ddt/ddthome.htm
(CDC diabetes home page)

http://www.disetronic.ch/Disetron
(Disetronic, insulin pump manufacturer)

http://www.lilly.com/diabetes
(Eli Lilly & Co.)

http://www.minimed.com
(Minimed, insulin pump manufacturer)

http://www.niddk.nih.gov/NIDDK_HomePage.html
(kidney info from NIDDK)

http://www.niddk.nih.gov/DiabetesDocs.html
(diabetes information from NIDDK)

http://www.deltanet.com/users/tdb
("The Outpost" blindness information)

Hardship Insulin Sources

Lilly Cares Program
Eli Lilly and Company
(800) 545-6962

For persons who need, but are unable to afford, their insulin, Lilly offers 3-month free supply, with the possibility of renewal. Eligibility determined by consultation with the individual's physician, who should phone Lilly Cares at the above number.

Novo Nordisk Pharmaceuticals Inc.
(800) 727-6500

For people who need, but are unable to afford, their insulin, Novo Nordisk will provide (one time only) a 3-month supply. Eligibility determined by consultation with the individual's physician, who should phone Novo Nordisk at the above number.

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SUGGESTED READINGS

Cleary, M. E. (Ed.). (1994). *Diabetes and visual impairment: An educator's resource guide.* Chicago: The American Association of Diabetes Educators - Education and Research Foundation.

Cleary, M. E., & Tuttle, N. (1994). *You, your eyes, and your diabetes* (Rev. ed.). Winnetka, IL: Hadley School for the Blind.

National Clearinghouse of Rehabilitation Training Materials. (1996). *Rehabilitation of individuals with diabetes.* Oklahoma City: Dean McGee Eye Institute.

Ponchilla, S. V. (1993). Complications of diabetes and their implications for service providers. *Journal of Visual Impairment and Blindness, 87,* 354-358.

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